ALZHEIMER'S DISEASE: PENNSYLVANIA PERSPECTIVE

HEARING

BEFORE THE

SUBCOMMITTEE ON
HEALTH AND LONG-TERM CARE

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

FIRST SESSION

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ALZHEIMER'S DISEASE: PENNSYLVANIA PERSPECTIVE

MONDAY, NOVEMBER 25, 1985

House of Representatives,
Select Committee on Aging,
Subcommittee on Health and Long-Term Care,
Erie, PA.

The subcommittee met, pursuant to notice, at 8 a.m., at Perry Square Auditorium, Erie Insurance Co., East 6th and French Streets, Erie, PA, Hon. Stan Lundine (acting chairman of the subcommittee) presiding.

Members present: Representatives Lundine and Ridge.

OPENING STATEMENT OF REPRESENTATIVE STAN LUNDINE

Mr. **Lundine**. The Subcommittee on Health and Long-Term Care of the House Select Committee on Aging will come to order.

I am Congressman Stan Lundine, and I represent the 34th Congressional District in New York, your neighbors for most of you.

I am pleased to join my colleague, Congressman Tom Ridge, in co-chairing this important hearing of the Subcommittee on Health and Long-Term Care of the House Select Committee on Aging, on which we both serve.

The subject of today's hearing, Alzheimer's disease, is one of great concern to our Nation's senior citizens and to the Nation as a whole. While Alzheimer's disease was first diagnosed in 1906, it is only recently that we have all become aware of the disease and the hardship it causes for those who are afflicted as well as for their families and friends.

It is important for public policymakers to have a clear understanding of this disease and its implications for health and aging policy at all levels. For this reason, I am looking forward to the testimony of the expert witnesses assembled here today.

The list of participants is impressive, including research specialists on Alzheimer's disease, health care professionals who have worked closely with patients, and those who have had to lend support in many ways to the patients and their families. I am particularly pleased to welcome two constituents of my own, and it was very nice of you to include those of us from the Empire State. I am pleased that you could offer your expertise and experience to today's proceeding.

I will also explain my own infirmity here. I am just proving that Joe Theismann is not the only old athlete in Washington who is hobbling around.

I will turn the chairing of this hearing over to Congressman Ridge.

STATEMENT OF REPRESENTATIVE THOMAS J. RIDGE

Mr. RIDGE. Thank you, Stan.

I certainly would like to thank all of you for attending what I am sure will be an informative and productive discussion of Alzheimer's disease, and I would like to again welcome my colleague, Stan Lundine, former mayor of Jamestown, now in his sixth term, representing that part of the Empire State, to join me in listening to the testimonies of those individuals who live and work on a day-to-day basis with Alzheimer's patients and whose true personal experience might help us better identify and better understand the turmoil of these patients and, as importantly, their family members.

Five years ago, if someone had asked the average person on the street if he or she knew what Alzheimer's disease was, I am sure the answer would have been I don't know. Today, however, Alzheimer's disease is no longer a silent epidemic.

Alzheimer's disease strikes 10 times as many Americans as does multiple sclerosis. This illness, barely known outside medical circles until recent years, accounts for more than half of the admissions to nursing homes in this country, afflicts between 1.5 and 3 million Americans, including those as young as 40 years old, and is responsible for the death of 120,000 people every year, making it the fourth leading cause of death after heart disease, cancer, and stroke.

Alzheimer's is a progressive, degenerative brain disease that, in many ways, may be the cruelest of all diseases because it kills its victims twice. In Alzheimer's, the mind dies first, as names, dates, and places are erased from one's memory. Then, the body dies. Elemental functions, such as walking, bathing, and eating, become almost insurmountable tasks.

What begins as a gradual loss of memory and has, in the past, been attributed to merely growing old, eventually progresses into disorientation, disfunction, and drastic changes in personality and disposition.

Sufferers of Alzheimer's unlearn even the simplest of skills, leaving them totally incapable of caring for themselves. In short, the disease robs its victims of their ability to think and often, therefore, their own humanity.

Recent demographic changes indicate that the number of Americans over the age of 65 doubled from 1950 through 1980, and is expected to double again by the year 2030. In light of these predictions, by the year 2000, it is estimated that 3.4 million Americans, 1 out of every 10 adults, over 65, will be a victim.

While medical sciences are beginning to make great strides, the cause of Alzheimer's remains unknown and a cure today is nonexistent. Furthermore, because of limitations inherent in the current structure of public programs, State and Federal, the Alzheimer victim and his or her family are provided inadequate financial assistance and help.

Given this myriad of problems, I am hopeful that this meeting will call attention to the difficulties faced by disease victims and their families. The testimony we will hear today will address a wide range of problems in this Nation's long-term health care policy upon which Alzheimer's patients must rely, the legal rights of these victims, institutionalization of Alzheimer's victims, and current research that is currently being carried out on the causes of the disease and improved treatment and care therapy.

There is hope for individuals with Alzheimer's, and each one of you here today plays an important role in making their hopes a reality. There exists a fundamental need for education and understanding at all levels, from the families and physicians to government officials, life insurance companies, and administrators of pension benefit funds.

Only through greater awareness of the pain and burdens of those afflicted will we see increased support for research and will the cause and cure for Alzheimer's be found.

Please be assured of my keen awareness of the burdens faced by victims and their families. I have joined several of my colleagues in sponsoring legislation that provides direct financial assistance to families caring for Alzheimer's victims as well as legislation that provides for continued research and training of professionals in the diagnosis and treatment of the disease.

Nowhere in our society are individuals left so unassisted and exposed to the hazards of catastrophic illness as are the victims of Alzheimer's disease. It is incumbent upon all of us to recognize that fact and to do everything in our power to change it.

Again, I want to welcome you and before we proceed with our first panel, I would like to describe for you how we will conduct the hearing.

We have two panels involving health care professionals, those involved with legal rights, research, and even some victims, family members of victims, who will testify.

Between the first and second panel discussion, we are going to take a recess and adjourn to the Atrium where we will have coffee and doughnuts, and then come back, after about 15 or 20 minutes.

For those of you in need of some restrooms, the facilities, if you go out to the back, through the Atrium, just walk across the hall and to your left, you will see a sign that says Exit, you do not want to take it all the way out the door, but if you follow that sign, you will see that the restrooms are out there.

I want to particularly thank Erie Insurance Exchange for their cooperation and thoughtfulness in providing this facility. I see my friend, Dana Lundquist, from Harrot Hospital. I want to thank you, Dana, for the coffee and doughnuts and, most importantly, I want to thank all of you who consider Alzheimer's disease important enough to take some of your time on this Monday morning to learn a little bit and help in the ongoing process, not only of continuing education, but working with family members, hospitals, health care institutions, and public policymakers in trying to address the real and personal problems of this disease.

With that, I would like to introduce the first panel and the first witness on the first panel. It is one of Congressman Lundine's constituents. I would like to introduce Ms. Martha Paulson. She is the director, the Jamestown Adult Day Care Center, Jamestown, NY.

Martha, welcome.

STATEMENT OF MARTHA PAULSON, DIRECTOR, JAMESTOWN ADULT DAY CARE CENTER, JAMESTOWN, NY

Ms. PAULSON. Thank you.

Congressmen, an adult day care center is an appropriate and extremely valuable service for Alzheimer's disease patients and their families.

At our center in Jamestown, we have served about 100 frail elderly, and approximately 25 of these have had a diagnosis of Alzheimer's disease or a related dementia. All of these affected individuals were living at home with their spouse or child, who was responsible for providing nearly all of the care of that person.

Families benefit greatly from respite offered by adult day care, by having a second person cared for by someone else, family members can catch up on needed rest, take time out to relax and enjoy themselves, and regain the emotional perspective that allows them to continue with a most difficult job.

By providing respite, adult day care helps the families to delay institutionalization of the Alzheimer's disease patient, thus allowing them to care for the person longer in the home.

Many of our clients, who have attended our center from 1 to 5 days per week, remained at home even when their functional abilities placed them at the skilled nursing level. Several family members told us that their affected parent or spouse would have been placed in a nursing home had it not been for our program, which allowed them to stay in the home for another year or more.

An additional benefit for families is for those care-givers who work and are afraid to leave the Alzheimer's patient unsupervised. They can attend day adult care every day and this frees the family member from worry about the person being home alone.

Another benefit for both the family and the patient is the availability of counseling and education concerning management of the disease from the staff of an adult day care center.

A final benefit of adult day care is that the Alzheimer's patient is helped to maximize his remaining abilities, such as social skills, mental abilities, physical health, and functional daily living skills.

Families have told us that the person attending our center was better at home, even on the days they were not at the center. They were more alert, more appropriate and less agitated, and they attributed this to the stimulation and socialization at adult day care.

An example of an Alzheimer's patient we serve in our center is a 62-year-old woman, who has had the disease about 5 years and lives with her husband, who is also 62. He brought his wife to our center because he works full-time and was concerned about her being home alone. She now comes to the center five days a week and has adjusted well. She is much happier and self-fulfilled. Her husband is grateful because he is working and is not forced into taking early retirement to stay home with her.

Another example of an Alzheimer's patient we serve is that of a 78-year-old woman living with her daughter. She has had extensive physical deterioration since she first began attending our program, and is currently confined to a wheelchair. She attends the program daily, so her daughter can go to college.

We provide help in meeting her daily needs, such as feeding, managing her incontinence, and encouraging her to begin walking again. Her daughter has been determined to keep her home, and we have provided her with considerable support and counseling.

Adult day care can serve as an alternative to institutionalization for the Alzheimer's disease victims, but not for all persons or in all stages of the disease. In general, institutionalization occurs most often due to social factors that compound medical problems.

Studies have shown that the typical participant in an adult day care program is very similar to the typical person in a skilled nursing facility as far as medical condition and functional abilities. This indicates that adult day care can serve as an alternative to institutionalization and also as an option in the continuum of long-term care.

Adult day care is also a very cost-effective way of caring for Alzheimer's disease victims and other frail elderly. Our fee for 1 full year of adult day care services, 8 hours per day, at 250 days per year is less than $4,000. This compares to an annual cost of institutional care, ranging up to $25,000.

Our center and other adult day care programs in New York State and other States face several problems in providing care to Alzheimer's disease patients and other frail elderly. One problem is the lack of legislation governing all types of adult day care programs.

Our center in Chautauqua County does not come under any government agency or department; we have no regulations, no certification, no licensure. Related to a lack of legislation is the major problem of inadequate funding.

Our center has been supported largely through foundation start-up grants. We have no identified source of long-term funding. We can demonstrate that we save Medicaid enough each year to support twice our annual budget, yet we are eligible for only a tiny amount of Medicaid funds under the current Federal waiver.

I do not personally feel that Medicaid should be the major funding source for adult day care for several reasons. I would rather see increased funding channeled through, say, area agencies on aging. Increased funding could allow existing centers to hire more staff, thus allowing them to serve Alzheimer's patients who need greater supervision and care.

In sum, adult day care has arisen as a grassroots alternative to meet an increasing need for long-term care of Alzheimer's patients. I encourage Federal, State, and local governments to assist day care providers in further developing and funding this vital service. Thank you.

[The prepared statement of Ms. Paulson follows:]

PREPARED STATEMENT OF MARTHA PAULSON, EXECUTIVE DIRECTOR OF THE JAMESTOWN AREA ADULT DAY CARE CENTER

Mr. Ridge and Mr. Lundine, my name is Martha Paulson, and I am the Executive Director of the Jamestown Area Adult Day Care Center a private, non-profit agency which provides adult day care services for frail elderly living in southern Chautauqua County. I currently serve on the board of directors for the Western New York Chapter of the Alzheimer's Disease and Related Disorders Association, and have been co-coordinator of the Jamestown Alzheimer's disease Family Support Group since it began in the spring of 1982. I am also a family member of a victim of Alzheimer's Disease; my father died three years ago after a seven-year progressive course of Alzheimer's Disease combined with multi-infaret demetia. This is my written testimony on the topic of Alzheimer's Disease related to the areas of long-term care services, particularly adult day care.

An adult day care center (or adult day services program) is an appropriate and extremely valuable service for Alzheimer's Disease patients and their families. At our center in Jamestown we have served about 100 frail elderly, and approximately 25 of these have had a diagnosis of Alzheimer's Disease or a related dementia. All of these affected individuals were living at home with a spouse or child, who was responsible for providing nearly all of the care for that person. Families benefit greatly from the respite offered by adult day care; by having the affected person cared for by someone else, family members can catch up on needed rest, take time out to relax and to enjoy themselves and regain the emotional perspective that allows them to continue with a cost difficult job. The book "The 36-Hour Day" by Nancy Mace and Peter Kabins which is the "bible" for Alzheimer's families, accurately portrays the caregiver's day as a 36-hour day rather than the 24-hour day, because every minute is spent in caring for or worrying about the affected person so that it seems each day is 36 hours long. By providing respite, adult day care helps the family to delay institutionalization of the Alzheimer's victim, thus allowing them to care for the person longer in the house. Many of our clients who have attended our center, from 1 to 5 days per week, remained at home even when their functional abilities placed them at the skilled nursing level. Several family members told us that their affected parent or spouse would have been placed in a nursing home, had it not been for our program which allowed them to stay in the home for another year or more.

An additional benefit for families is for those caregivers who work and are afraid to leave the Alzheimer's patient unsupervised. They can attend adult day care every day and this frees the family member from worry about the person being home alone. Another benefit for both the family and the patient is the availability of counseling and education concerning management of the disease from the staff of an adult day care center. A final benefit of adult day care is that the Alzheimer's patient is helped to maximize his remaining abilities such as social skills, mental abilities, physical health and functional daily living skills. Families have told us that the person attending our Center was "better" at home even on the days they were not at the Center; they were more alert, more appropriate, and less agitated, and they attributed this to the stimulation and socialization of adult day care.

An example of an Alzheimer's patient we serve in adult day care is that of a 62-year-old woman who has had the disease about 5 years and lives with her husband who is also 62-years-old. He brought her to our center because he works full-time and was concerned about her being home alone, and he had to leave work at least once or twice a day to go home and check on her. She now comes to adult day care 5 days a week and loves it; she believes she is there to help others and we encourage her to do as much as she can, including washing dishes, helping direct other clients in tasks, doing simple crafts and baking, exercising, and enjoying the company of other people. She cries much less now and appears to be happier and more self-fulfilled. Her husband is grateful he can keep working and was not forced into taking early retirement to stay home with her.

Another example of Alzheimer's patient we serve is that of a 78-year-old woman who has been in our program for 7½ years. She lives with her daughter and has experienced considerable physical deterioration since we first encountered her. She is currently confined to a wheel chair following a hip replacement this past summer, and she also attends the day care program every day so her daughter can go to college. We provide help in meeting her daily needs such as feeding, changing her incontinence pads, and encouraging her to begin walking again, which requires the assistance of two aids. She continues to surprise us with her progress and her maintained level of alertness; she is unable to communicate well with others, but responds to various stimuli and activities offered to her. Her daughter has been determined to keep her at home, and we have provided her with considerable support and counseling through the Center and the family support group.

Adult day care can serve as an alternative to institutionalization for the Alzheimer's Disease victim, but not for all persons or in all stages of the disease. We have served persons at our Center with a variety of dementia-like symptoms; some have adjusted well and are handled easily—others have adjusted poorly and required almost one-to-one supervision so that they didn't climb out the windows, wander away from the building, or hurt themselves in other ways. Several clients have been with us up to and including the latter stage of the disease where physical deterioration occurs; in other instances, this became too much for the family caregiver to handle and the person was placed in a nursing home. Individual patients and families vary in their resources and skills, so that a family may or may not be able to cope with a very disruptive family member. In general, institutionalization occurs most often due to social factors that compound a medical problem, such as lack of finances, lack of family support, inadequate housing, inadequate support services, etc. Studies have shown that the typical participant in an adult day care program is very similar to the typical person in a skilled nursing facility, as far as medical condition and functional abilities. This indicates that adult day care can serve as an alternative to institutionalization, and also as an option in the continuum of long-term care.

Adult day care is also a cost effective way of caring for Alzheimer's Disease victims and other frail elderly individuals. Our fee for a full year of adult day care service (6 hours per day, 250 days per year) is only $3,750. This compares to an annual cost of institutional care ranging from $13,000 to $25,000. Or, if private care is provided in the home such as a nurses aide through an agency, the cost for the same number of adult day care hours is about $12,000.

Our Center and other adult day care programs in New York State and other states, face several problems in providing care to Alzheimer's Disease patients and other frail elderly. I will list these with suggestions that could be explored at the federal and state level to deal with them.

1. New York State currently has no legislation concerning adult day care problems other than those certified as Subchapter C programs in skilled nursing or health-related facilities. This is dangerous because any service being provided to vulnerable frail elderly has the potential for abuse. In addition, lack of legislation in New York State also means there is not a formal mechanism in place for encouraging the start-up of additional adult day care centers. Perhaps the federal government could mandate that states develop more comprehensive adult day care initiatives to increase the number of centers and promote the utilization of those in existence.

2. Lack of state regulation also results in limited funding available to free-standing adult day care programs in New York State. A federal waiver does exist that allows Medicaid reimbursement for adult day care: individual states are apparently able to apply this as they desire, and in New York it is limited to the Health Department's Long Term Home Health Care Program or Subchapter C programs (those in nursing homes). Our Center receives Medicaid only for a small number of clients enrolled in the Long Term Home Health Care Program (limited to 50 in the entire county), yet nearly half of our clients are at the Medicaid level. This federal waiver is up for renewal this year, and I would encourage that it be renewed; I would also hope that New York State would consider expanding its application to all Medicaid-eligible persons using adult day care services. This is justified by the savings adult day care can realize for Medicaid, by delaying institutionalization and serving as a substitute for home care in some instances. On the other hand, I feel that in the long run, Medicaid may not be the best source of long-term funding for adult day care, or for other services required by Alzheimer's patients and other frail elderly. Historically, funding has followed medically-oriented programs and treatments, yet the availability of social supportive services has a greater impact on delaying the institutionalization of the Alzheimer's Disease victim. Therefore, I believe that governmental support of aging programs at the federal, state, and local level, should be geared to programs and services more in the traditional domain of the Office for the Aging (adult day care, homemaker services, nutrition, transportation, case management and referral, counseling, housing, etc.) rather than those in the medical domain. This is especially true of the needs of the Alzheimer's Disease patient and family, who benefit most from respite services and family support. Both of these services developed at the grass roots level to fill a need and have been supported primarily by volunteers and private donations. The need is much greater, however, so government support must occur if the need is to be met.

It would be helpful if a uniform government funding were made available through New York State. For example, in Cattaraugus County, the adult day care center in Olean receives 85 percent of its yearly budget through government sources including Title III, Title XIX, Title XX, and Community Services for the Elderly funds. In Chautauqua County our Center receives only 30 percent of its budget from government sources, and the remainder from private sources that have no guarantee of being renewed from year to year.

3. A third problem faced by adult day care centers in caring for Alzheimer's victims is that of caring for the "disruptive" or "difficult" patient. Since adult day care programs involve gathering a group of people together in one place, an individual who is consistently inappropriate or agitated can be upsetting to others in the group. There is also the problem of supervising such an individual who may try to leave the center, eat objects that are not food, or in other ways harm themselves. Setting up Centers specifically for these types of patients may be helpful but not practical for rural areas; in particular, allowing increased funding through grants for existing centers to add on supervisory staff and add on space for specific Alzheimer's programming might be a satisfactory solution to the problem.

4. A fourth problem adult day care centers face, is that many smaller communities lack resources for education of staff and families about caring for an Alzheimer's Disease victim. Many adult day care programs refuse admission to those diagnosed as having Alzheimer's Disease, and I believe this is because they are unfamiliar with the management and care of such a person. If the government were to provide grants so that the trainers from aging centers could visit rural areas to provide in-service education and family teaching about Alzheimer's Disease, this would be of great benefit to adult day care staff and families of those they serve. We have an excellent program at the State University of New York at Buffalo in the Center for the Study of Aging, yet my staff and client families are not able to drive 140 miles round-trip to take advantage of this very often. We need to hold training sessions locally and on a regular basis.

A larger problem is the lack of local resources to provide on-going Alzheimer's Disease counseling, information, and referral in our county. Alzheimer's Disease is not treated medically but behaviorally; no one person, agency, or facility is designated to do this locally. In Chautauqua County, Marie Forhan and I have developed this role for ourselves on a volunteer basis; we cannot devote enough time to it when you consider the possible number of Alzheimer's victims in our county could be between 3,000 and 7,300 (2 to 5 percent of the general population). Hospitals, social service agencies, even physicians refer people to us for counseling and support, and the need is growing so rapidly we feel it could easily be a full-time job for one or more persons in our area. Chapters of the ADRDA could oversee such a counseling program, and it would help if any amount of government support could be tapped for this purpose.

Other problems that Alzheimer's patients and their families face include:

1. Inadequate, inconsistent, and detrimental care in skilled nursing homes, hospitals, and state psychiatric facilities. Many complaints from our family support group are centered around this issue, and include reports of facilities where Alzheimer's residents who wander are restrained for long periods of time without adequate exercise, or care is not given to maintaining adequate nutrition because of difficulty in feeding. The disruptive patient is also not accepted by many facilities other than the state-run psychiatric hospitals, which may not be adequately staffed to provide enriching socialization and activities for the Alzheimer's patient. I would suggest that standards of care for Alzheimer's victims in institutions be developed with strict monitoring for compliance.

2. Impoverisation by a health care system that has not yet recognized Alzheimer's Disease as a disease. Many private insurance companies as well as Medicare do not cover the services an Alzheimer's patient requires (such as day care, nursing home care, respite home care, incontinence supplies, etc.) because the care is considered custodial rather than skilled, and Alzheimer's is not considered a catastrophic illness. Anyone who has ever cared for an Alzheimer's patient could tell you the care requires highly developed management techniques and knowledge of the disease process, and as a terminal illness it certainly qualifies as being catastrophic. It is very unfortunate that in states such as New York one spouse that requires long-term care can essentially impoverish the remaining spouse living in the community. I hope that the federal government would review the definition of a catastrophic illness and include Alzheimer's Disease in this category; also allowing for more Medicare reimbursement and revising Medicaid laws to reduce impoverishment of the well spouse of an Alzheimer's victim.

3. Inconsistent and inadequate medical care and diagnosis concerning Alzheimer's Disease and related dementias. Physician training is inconsistent regarding gerontology and Alzheimer's Disease; we have found quite a variety in physicians' abilities to manage the Alzheimer's patient in our own country. Diagnosing the disease is not consistent, so how we gather valuable statistical data on incidence and disease progression? Making physician training mandatory in treating and diagnosing Alzheimer's Disease would held alleviate this problem, as would the establishment of regional Alzheimer's Disease treatment centers.

4. Lack of other respite and supportive services for Alzheimer's victims and their families. In Chautauqua county we have two "respite beds" at a local nursing home; families can take the patient there for periods up to one month, thus allowing them to take vacations or have care for the person if they become temporarily ill. Encouraging more facilities to offer this service, as well as in-home respite aides with flexible hours and reasonable cost, would be greatly valued by family members.

Mr. RIDGE. I want to thank you, Martha.

What we will do is complete the testimony from the entire panel, and then open up to questions. I might note for Ms. Paulson as well as for the—those in attendance that your entire testimony, I know you paraphrased quite a bit of your testimony, I appreciate that, and for all witnesses, your entire testimony will be included as part of the record and proceed to you, Mr. Morrow.

Mr. MORROW. Thank you.

Mr. RIDGE. I should say, announce that Mr. Robert Morrow is the Administrator of the Ball Pavilion here in Erie, PA. Bob.

STATEMENT OF BOB MORROW, ADMINISTRATOR, THE BALL PAVILION, ERIE, PA

Mr. MORROW. Thank you.

I am Bob Morrow, and I represent the services of Brevillier Village. Ball Pavilion is a nursing care facility, also the Conrad House, a retirement center, Brevillier Home Health Services, Barnabas Court care facility, and also soon Brevillier Village adult day care center.

We are an Episcopal-sponsored, nonprofit-retirement community here in Erie County.

I would like to speak to you briefly this morning about the disease and the complexity of providing care to its victims.

With approximately 3 million Americans estimated to be suffering from Alzheimer's disease, and as many as 8 million more directly affected by it, we must recognize the magnitude of the problem and the importance of national attention in the study of causes, cures, and treatments.

The placement of advanced Alzheimer's patients in long term care facilities has focused public attention on the nursing home industry. The often intensive, specialized level of care required by Alzheimer patients has placed doubt among providers about the appropriateness of such placement in homes for the aging.

Alzheimer's is a national tragedy which affects not only the aging, but nonelderly adults also. Understanding that it is, indeed, a tragedy at any age is an obstacle we must first overcome.

Perhaps a brief description of a true story will provide support for the recommendations that will follow.

A local successful businessman was found by the Ohio State Police one early winter without proper identification or clothing, driving the wrong way on the interstate, on his way, as he reported, to Florida.

When returned to home, the family had recognized the victim's gradual deterioration and had turned to our facility for our assistance. The family was exhausted by their attempt to cope and provide support in the home. The patient was already living a nightmare of confusion in a disease which cruelly pushed him from moments of lucid recollection into longer and longer periods of total disorientation.

The disease which attacks memory and intellect in the early stages progresses through the complex stages of destruction, robbing the victim of communication, motor skills, and, finally, basic body functions.

Our subject followed through these classic phases with memory impairment, lack of judgment, language difficulty and personality change. The family was watched to linger in several of the phases referred to in the negative coping process, being guilt, anger, denial, grief, distance and, finally, separation.

Following the loss of speech, our patient soon was unable to ambulate. Restrained for safety, the victim kept arms and legs in constant motion. Incontinence was followed by the loss of ability to swallow, and death came finally as a welcome relief from months of suffering and agony, providing the patient with at least peace, but leaving the family exhausted and ridden with guilt, emotionally and financially drained.

The problem of providing care is as complex as the disease itself. Alzheimer's patients require perhaps 2 to 1 the hands-on kinds of service and assistance that are required by other geriatric patients. The constant, intensive kinds of complete care do not qualify as skilled nursing services under the definition set forth by the Pennsylvania Department of Public Welfare.

Frustration, conflict and finally desperation often characterize the relationship between families and the facilities, between staff and the patients.

I fear that when providers recognize the labor intensive and often unreimbursed level of care required by Alzheimer's patients, that an unfortunate but predictable selective discrimination against them may occur, denying those who truly need access to long-term care facilities.

Although nursing home placement is not the only option available to Alzheimer's patients, most victims will require some type of institutionalized care in the final stages of the disease. We, as providers, are called on to make a difficult decision, to avoid the problem through a selective admission process, or to accept the challenge, be innovative and resourceful, in attempting to provide a meaningful continuum of care to the tragic progression of the disease. From onset and diagnosis, through all the complex changes and phases.

Until researchers some day find a cure, there are five things I believe we must work on together, avoiding at all costs the possibility of warehousing Alzheimer's victims in nursing homes across the country.

No. 1. Community education. Making the public aware of Alzheimer's disease is immediately important. Public policy will make available funds for research, testing and, hopefully, a cure, which will come from public support from the devastating consequences of this disease are understood at the grassroots community level.

The difficult decisions which must be made by legislators will be made easier with the community support.

No. 2 is patient involvement. Early diagnosis will soon allow patients to become involved while the disease still provides them the option. From a legal perspective, we must work to guarantee the rights of patients to know and understand their disease, to grieve and to be supported, to plan their use of resources and their course of treatment, decide what treatment should be provided, withheld or refused, and if they choose, to be permitted to participate in research.

No. 3. Training and support care-givers. We should realize that when a primary care-giver can be identified, normalization of life to the Alzheimer's victim can most successfully occur in the home environment. Training programs for care-givers will provide them with the essential basic skills to maintain an Alzheimer's patient safely and comfortably in their home.

The need of both the patient and the care-giver are recognized with the special services of home health care and adult day care, to provide medical and social care to the victim while providing respite and support to the care-giver.

No. 4. Quality medical care. We must call on our medical schools, teaching hospitals, nursing and other professional training programs, practitioners and providers, to recognize the special needs of Alzheimer's, and to incorporate in their curriculum and their care plans the very complex treatment needs of these patients.

We must to work the minimize excess disability by diagnosing the co-existing illnesses which often compound the suffering by accompanying Alzheimer's disease. The treatable conditions, such as depression, arthritis, infections, and the side effects of drug therapy, should not be allowed to pass by under the disguise of total devastation which characterizes Alzheimer's disease.

No. 5. Quality long term care. Often, the final stages of Alzheimer's progression requires institutionalization of patients. In the long term care setting, it will be our responsibility to develop specialized treatment programs which will successfully balance the medical and social care needs of each patient.

Our challenge will simply be to maximize the care while minimizing the cost. We will be responsible for setting an acceptable standard for a disease whose symptoms change often on a daily basis. We will be called on to make environmental adaptations to guarantee safety and comfort to a patient who is very much unlike those we have cared for in the past.

We must develop special training for our staff and promote an understanding and sensitivity among our communities, volunteers, and families. We must, at the same time, prevent the denial of access to services by Alzheimer's patients in the name of convenience or cost containment.

I fear that many will turn away from the challenge, discouraged by the cost, the risk, and perhaps the political climate. I would call on my colleagues to be willing to take chances, but to do so, we must call on our political leaders first to provide legislation which will ensure cooperation among medical and professional communities by promoting research, community education, patient involvement, training, support for care-givers, and innovations in the treatment of Alzheimer's patients.

Only in an atmosphere of cooperative interaction, free from the conflict of partisan politics, provider profits, and mutual distrust, can we expect to successfully develop a responsible approach to care for Alzheimer's victims.

I call on you today to recognize Alzheimer's disease as a great American tragedy, and to approach it in your discussions and debates with the same sense of commitment and resolve that you would approach any other national disaster.

I thank you for the opportunity to address you here today, and pray for you in the difficult decisions you must make. Thank you.

[The prepared statement of Mr. Morrow follows:]

Prepared Statement of Bob Morrow, Nursing Home Director of Ball Pavilion

I am Robert Morrow, the Administrator of The Ball Pavilion, an 84-bed skilled nursing and intermediate care facility at Brevillier Village, an Episcopal Cathedral of Saint Paul. In addition to the health care facility at Brevillier Village, I represent Conrad House, a 133 unit elderly apartment complex, Barnabas Court, a 57 unit personal care facility, Brevillier Village Home Health Services, providing 400 home health visits per month, and the Brevillier Village Adult Day Care Center scheduled to open in 1986.

These service programs of Brevillier Village which I speak for today provide residential, nursing and home health services to approximately 500 adult and elderly persons throughout Erie County. Brevillier Village is an active member of the Pennsylvania Association of Non-Profit Homes for the Aging [AAHA]. It is a concerned member of these associations and as a provider of non-profit health care that I speak to you today about Alzheimer's Disease. I will defer any discussion of the etiology of the disease to the medical experts and will instead devote my brief time to the complexity of the disease as it relates to the provision of care.

With 3 million Americans estimated to be suffering from Alzheimer's Disease, and as many as eight million directly affected by it as family caregivers of professional service providers, we must recognize the magnitude of the problem and the importance of national attention in the study of causes, cures and treatment. The placement of advanced Alzheimer's patients in long term care facilities has focused public attention on the nursing home industry. The often intensive and specialized level of care required by the Alzheimer's patient has placed doubt among providers about the appropriations of such placements in homes for the aging.

Alzheimer's is a national tragedy which affects not only aging but non-elderly adults also. Understanding that it is indeed a tragedy at any age is an obstacle we must first overcome. Breaking through the stereotypic acceptance of suffering and disease in aging will allow us to study and treat Alzheimer's Disease compassionately and conscientiously, regardless of the victim's age. Perhaps a brief description of a true story will provide support for the recommendations that will follow.

A bright successful businessman, a father, a grandfather, a community leader, a church supporter, was found by the Ohio State Police one early winter without identification or proper clothing, driving the wrong way on the interstate on his way, he reported, to Florida. When returned to home, the family who had recognized the victim's gradual deterioration, physically and intellectually, turned to our facility for assistance. The family was exhausted by their unsuccessful attempt to cope and provide support in the home. The patient was already living a nightmare of confusion in a disease which cruelly pushed him from moments of lucid recollection into longer and longer periods of total disorientation. The disease which attacks memory and intellect in the early stages progresses through its complex phases of destruction, robbing the victim of communication, motor skills and finally basic body functions. Our subject followed through the classic phases of the disease with memory impairment, lack of judgment, language difficulty, personality change, until family and friends were no longer recognized. The family was watched to linger in several of the phases referred to in the negative coping process, being guilt, anger, denial grief, distance, and finally separation. Following the loss of speech our patient soon was unable to ambulate. Restrained for safety, the victim kept arms and legs in constant motion. Incontinence was followed by the loss of ability to swallow so that spoon feeding became an impossible task. Death came finally as a welcome relief to months of suffering and agony, providing the patient at last with peace but leaving the family exhausted, ridden with guilt, emotionally and financially drained.

The problem of providing care is as complex as the disease itself. Alzheimer's patients require perhaps two to one the hands-on-kind of service and assistance that are required by other geriatric patients. The constant intensive kinds of complete care required by Alzheimer's patients do not qualify as skilled services under the definitions set forth by the Pennsylvania Department of Public Welfare. Frustration, conflict, and finally desperation, often characterize the relationship between families and the facility, between staff and the patient which become all consuming and difficult from the date of admission. I fear that when providers begin to recognize the labor intensive and often unreimbursed level of care required by Alzheimer's patients that an unfortunate but predictable selective discrimination against Alzheimer's patients may occur, denying those who truly need services access to long term care facilities.

Although nursing home placement is not the only option available to Alzheimer's patients, most Alzheimer's victims will require some type of institutionalization in the final stages of the disease. We as providers are called on to make a difficult decision to pursue the risk-free path of avoiding the problem through a selective admission process, or by accepting the challenge to be innovative and resourceful attempting to provide a meaningful continuum of care through the tragic progression of Alzheimer's disease from onset and diagnosis through each of the complex changes and phases to the inevitable conclusion—the victim's death. Until researchers someday find a cure, there are five things we must work on together, avoiding at all costs the possibility of warehousing Alzheimer's victims in nursing homes across the country.

1. Community education.—Making the public aware of Alzheimer's disease is immediately important. Public policy which will make available funds for research, testing, and hopefully a cure for Alzheimer's will come from public support when the devastating consequences of this disease are understood at the grass roots community level. The difficult decisions which must be made by legislators will be made easier with community support.

2. Patient involvement.—Early diagnosis will soon allow patients to become involved while the disease still provides them with the option. From a legal perspective we must work to guarantee the rights of patients to know and understand their disease, to grieve and to be supported to plan their use of resources and their course of treatment, to decide what treatment should be provided, withheld, or refused and if they choose, to be permitted to participate in research.

3. Training and support to caregiver.—We must realize that when a primary caregiver can be identified, normalization of life for the Alzheimer's victim can most successfully occur in the home environment. Training programs for caregivers will provide them with the essential basic skills to maintain an Alzheimer's patient safely and comfortably in the home. The needs of both the patient and the caregiver are recognized in the special services of home health care and adult day care that provide medical and social care to the victim while providing respite and support for the caregiver.

4. Quality medical care.—We must call on our medical schools, teaching hospitals nursing and other professional training programs, practitioners, and providers to recognize the special medical needs of Alzheimer's patients and to incorporate in their curriculum and care plans the very complex treatment needs of Alzheimer's patients. We must work to minimize the "excess disability" by diagnosing the coexisting illnesses which often compound the suffering by accompanying Alzheimer's disease. The treatable conditions such as depression, arthritis, UTI's and the side effects of drug therapy should not be allowed to pass by under the disguise of total devastation which characterizes Alzheimer's disease.

5. Quality long term care.—Often in the final stages of Alzheimer's progression the institutionalization of patients is necessary. Long term care administrators may find themselves involved in any role of the five steps along the continuum described. In the long term care setting, it will be our responsibility to develop specialized treatment programs which will successfully balance the medical and social care needs of patients. Our challenge will simply be to maximize the care, while minimizing the cost. The cost of care today for these patients varies from $40 to $120 a day. We will be responsible for setting an acceptable standard for a disease whose symptoms change often on daily basis. We will be called on to make environmental adaptations to guarantee safety and comfort to the patient who is very much unlike those we have cared for in the past. We must develop special training for our staff and promote an understanding and sensitivity among volunteers and families. We must at the same time prevent the denial of access to services by Alzheimer's patients in the name of convenience or cost containment.

I fear that many will turn away from the challenge, discouraged by the cost, the risk, and the political climate. I would call on my colleagues to be willing to take chances and their boards to support them, but to do so we must call on our political leaders to provide legislation which will ensure cooperation among medical professionals in the community by promoting research, community education, patient involvement, training and support for caregivers, and innovation in the treatment of Alzheimer's patients. Only in an atmosphere of cooperative interaction free from the conflicts of partisan politics, provider profits, and mutual distrust, can we expect to successfully develop a responsible approach to care of Alzheimer's victims.

I call on you today to recognize Alzheimer's disease as a great American tragedy and to approach it in your discussion and debate with the same sense of commitment and resolve that you would approach any other national disaster. I thank you for the opportunity to address you here today and pray for you in the difficult decisions you must make. Thank you.

Mr. Ridge. Thank you very much.

I have several questions that I would like to follow up on, but we will move on to our next witness, Ms. Marie-Theresa Forhan, founder of the Jamestown Area Support Group, Bemus Point, NY. Welcome.

STATEMENT OF MARIE-THERESA FORHAN, FOUNDER, JAMESTOWN AREA SUPPORT GROUP, BEMUS POINT, NY

Ms. Forhan. Congressmen, I am here today to represent my Jamestown Area Support Group my families of Jamestown, NY, Warren, PA, Dunkirk, Mayville, Westfield, Cattaraugus.

Until just a few years ago, Alzheimer's disease was for the old folk, you know, hardening of the arteries and even insanity; but, now, Dr. Alzheimer and our modern medicine do not agree with that. We know it is the death of the brain cells. The patient dies every day over a period of 7 to 10 years.

No more thinking, no more communication. Dr. Manning, the expert neurologist told my group that there is no cure and no hope. So, because of the desperate fate, hospitals, insurance industry, and Medicare will not have anything to do with us. I think this is sheer discrimination. I know Alzheimer's disease is a long-term disease, but I know other ones which are just as long. Lou Gehrig, M.S., palsy, Downs' syndrome. I believe it is discrimination.

Now, what about the care giver, the person in charge? I know it is a challenge and a privilege to take care of a sick person, but it is hell. It is a 36-hour-a-day position. It really is. I wish I had today some of my group members with me. You could be really shaken.

So, the care giver can either be the spouse or if the victim is a widowed person, it is going to be up to one family member to care for the patient, and this way, there are problems because some children will not recognize that their father or mother are not right. They will not accept it at all, and it is a case of embarrassment. The neighbors say, "Oh, my. I heard that." I heard even worse remarks.

My members can hardly make it to the meeting, which we have once a month for 2 hours. They have to find a sitter able to care for a demented person; and where do you find it? The rate is $4 an hour.

So, there is option, the nursing home at $30,000 a year. Now, my figures are right because I had an interview with three nursing homes. If you keep your patient at home, it is not only difficult, it is very expensive. The patient is incontinent and the diapers alone cost $70 a month. I have the right figure for that, too.

And, of course, it is taking a great load on the care giver, which is about losing his health, his mind, or her mind, and I think it is a must for those people to have some kind of a respite, some rest, but where? Where are you going to put your patient while you get your rest?

We have only two respite relief beds in Chautauqua County. I did not say Jamestown. I said Chautauqua County. Two beds, $70 a day, and, there, it is at the Lutheran Social Services. So, it is really a great, great problem.

My motto is "Ask and ye shall receive." I thank you, Congressmen, to have given me today the opportunity to ask.

[The prepared statement of Ms. Forhan follows:]

PREPARED STATEMENT OF MARIE THERESA FORHAN, FOUNDER OF THE JAMESTOWN AREA ALZHEIMER'S DISEASE SUPPORT GROUP

Gentlemen, Alzheimer's Disease, named for it's discovered, Dr. Aloysius Alzheimer of Germany, seems to constitute the slow death of the brain cells of its victim. Until the rather recent discovery, the victim was considered to be experiencing "early senility."

It seems to select its victims at random and can suddenly appear in an older or middle aged member of anyone's family.

This sudden, shocking change in a family member invariably causes severe trauma within the family. Some of the younger members are unable to accept, or cope with the fact that dad or mom are no longer "with it."

The purpose of an Alzheimer's Disease Support group is to help the families of the victim, to cope with the life that has suddenly been thrust upon them. A situation which at present has no cure and will end only upon the death of the victim. There are no known treatments available but some prescription drugs are sometimes given. In the meantime, months, and often many years, of almost intolerable life ensues.

When I founded the Jamestown, New York, support group in 1981, my purpose was to assist and comfort these families, by providing them with what information was available pertaining to their problem and providing them with a few hours of relief and contact with others who were experiencing similar problems. The group meets once a month. There is absolutely no charge for membership or attendance at the meetings. I feel that we should meet more frequently but it is very difficult to find reliable "sitters" to stay with the victim. Some Alzheimer victims are prone to wander away and become completely lost. I advise families to be in touch with the police in the event that the patient should wander away or become violent, which sometimes happens with some cases. There have been cases where police have mistaken an Alzheimer patient, wandering around, for an intoxicated person.

I feel that some of the assets provided by my Support Group are:

Two hours of communication with the real, outside, world.

A chance to peacefully share a cup of coffee and a laugh, but mostly to provide information about finding doctors, clinics, addresses of places where necessary equipment can be rented or purchased and a knowledge of handling drugs and prescription medicines.

Almost every month I provide a speaker such as an attorney to discuss such matters as Power of Attorney (Standard or Durable), estate succession, testamentary and living trusts, and how to preserve some of the family's assets.

We also have had speakers who are experts in Social Security, S.S.I., and Medicare and Medicaid.

We have also had speakers who discussed the painful subject of the possibility of the disease being somewhat hereditary.

In addition to the obvious physical problems to be endured by the family, who are now on duty twenty four hours a day, is the financial drain, and often ruin, which the disease will cause. At present very little financial assistance is available to Alzheimer Disease victims and their families. The illness is not covered by Blue Cross and Blue Shield or Medicare. Sometimes the family's assets are in the name of the victim, causing grave legal problems.

A very painful subject to be confronted is the Nursing Home dilemma. Fees run about $70 per day. A Respite Room is also about $70 per day. There are only two Relief Beds in Chautauqua County. It is a very painful matter because who knows when the care giver will not be able to care for the patient even for a few days at a time—or just to take a break?

The bills are very high when it comes to buying or renting equipment. Just to name a few from a survey:

Rental of hospital bed, monthly	$130
Commode, monthly	25
Purchase of commode	90
Purchase of wheelchair	500
Diapers:	
Per 10	7
Monthly	70
Daily help, monthly	800
Unemployment insurance, per year	1,200
Day care center, per day (in addition to the fact that the care giver has to leave his or her job to attend to the victim's needs)	15

Gentlemen, I thank you deeply for this God given opportunity to side with my Alzheimer's people. God watch over you, that you may never be crippled by this disease.

Please accept this expression of my respectful feelings.

Mr. **Ridge**. Thank you. Thank you very much, Mrs. Farhan.

I would like next to introduce Ms. Tamara Lehman, Nurse practitioner-director, Alzheimer's Support Group here in Erie, PA.

Ms. Lehman.

STATEMENT OF TAMARA LEHMAN, NURSE PRACTITIONER/PROFESSIONAL ADVISOR, ALZHEIMER'S SUPPORT GROUP, ERIE, PA

Ms. **Lehman**. As a representative of St. Vincent's Geriatric Health Service, I would like to thank Congressman Ridge and Congressman Lundine for giving me the opportunity to testify on Alzheimer's disease.

The plight of the Alzheimer's family is coming out of the darkness thanks to efforts such as this.

Imagine, if you would, an active, healthy, successful 60-year-old accountant, who can no longer balance a check book. A husband of 56 years who repeatedly asks his wife, do I know you. The kind and gentle man who is now combatant and violent without provocation. The meticulous grandmother of five who can no longer dress herself and has no control over bodily functions.

Imagine, if you take your loved ones to the physician's office because they are becoming more forgetful, wandering the neighborhood, or just not themselves, seemingly losing control, they are unaware of time and place and perhaps depressed that they realize something is wrong.

Your physician advises you that a dementia workup will be done, which will include a history and physical, a battery of lab work, neurological testing, psychological testing, and perhaps a CAT scan, and this will cost you or your insurance company from $500 to $750.

Imagine, going through all of the dementia workup and being advised that all is normal, there is nothing treatable or reversible. You think the patient must be acting, putting us all on, only to feel guilty when the physician tells you this could be Alzheimer's disease, that we are unable to accurately diagnose Alzheimer's disease and can only confirm the diagnosis on autopsy. That the purpose of the dementia work-up was to find treatable causes of the confusion or dementia.

Imagine, your worst fears realized when the physician tells you that your loved one probably has Alzheimer's and there is no treatment. Medications will help control some behavior, but will not treat the disease, and your best alternative is to join a family support group to learn how to manage the Alzheimer's patient.

Imagine, learning that you do not know the cause of Alzheimer's disease, but there are several theories. A slow-growing virus, a genetic theory, chemical theory relating to too much aluminum or too little acetylcholine. Research is being done, there is hope.

Ten years ago, the family would have been told that confusion is normal in aging, or that hardening of the arteries causes it, or that the patient was just getting senile. Medical science is looking for the answers, but more money is needed for research.

Imagine, learning that your loved one will progress from being forgetful to total confusion, and, in the final stages of the disease, will be demented, totally dependent for care, unable to control bodily functions, unable to eat or communicate, and totally disoriented, and will finally die physically long after the mind has ceased to function, due to infection or other complications.

This process called Alzheimer's is a slow one, from 8 to 10 years. During the course of the disease, the family will exhaust their assets, their friends, because no one wants to be around the Alzheimer's patient, and their emotional and physical health, trying to manage a person who does not even know them any more.

Imagine the guilt when you finally must place your loved one in a nursing home, the pain when the nursing home calls and says they can no longer handle your loved one because he is too disruptive or too dangerous to patients and staff.

Imagine, your only hope is that when someone at the Alzheimer's support group may have had the same experience and can help you. They will at least listen to you because there are no easy answers.

As professional advisor to the Erie Family Support Group, I am concerned, concerned that as our population ages and the number of Alzheimer's victims increases, will we have community resources for them? Day care, respite care, and home health care are desperately needed already if we are to maintain these patients at home.

What will the future bring? Four years ago, when St. Vincent's Health Center became involved in the Alzheimer's support group, there were a handful of family members. Now, we have a mailing list of over 120, and an average meeting attendance of 35, and we have just applied to affiliate with the National Alzheimer's Disease and Related Disorders Association.

We are trying to meet the needs of the Alzheimer's families, but we need your help.

Thank you for giving me this opportunity.

[The prepared statement of Ms. Lehman follows:]

PREPARED STATEMENT OF TAMARA LEHMAN, CRNP SAINT VINCENT HEALTH CENTER

Thank you Congressman Ridge and Congressman Lundine for giving me this opportunity to testify on Alzheimer's disease. The plight of the Alzheimer's family is coming out of darkness thanks to efforts such as this.

Imagine—an active healthy, successful, 60-year-old accountant who can no longer balance a check book. A husband of 56 years who repeatedly asks his wife, "Do I know you?" The kind, gentle man who is now combative and violent without provocation. The meticulous grandmother of five who can no longer dress herself and has no control over bodily functions.

Imagine—you take your loved one to the physician's office because they are becoming more forgetful, wandering the neighborhood, or "just not themselves". Seemingly, losing control, they are unaware of time, place and perhaps depressed as they realize something is wrong. Your physician advises you that a dementia work-up will be done which will include: a history and physical, a battery of lab work (Complete Blood Count, Chemical Profile, Thyroid Function Test, Urinalysis, S-12 Level, Folate Level, EKG), neurological testing, psychological testing and perhaps a CT Scan, and this will cost you or your insurance carrier from $500-$700.

Imagine—going through all of the dementia work-up and being advised that all is normal, there is nothing treatable or reversible. You think the patient must be acting, "putting this all on", only to feel guilty when the physician tells you this could be Alzheimer's Disease: that we are unable to accurately diagnose Alzheimer's in life and can only confirm the diagnosis on autopsy, that the purpose of the dementia work-up was to find the treatable causes of dementia.

Imagine—your worst fears realized when the physician tells you that your loved one probably has Alzheimer's and there is no treatment, medications will help control some behavior but will not treat the disease, and your best alternative is to join a family support group to learn how to manage the Alzheimer's patient.

Imagine—learning that we don't know the cause of Alzheimer's disease—that there are several theories (1) a slow-growing virus, (2) genetic, (3) chemicals—either too much aluminum or too little acetylcholine. Research is being done. There is hope. Ten years ago the family would have been told that confusion is: normal in aging, or that hardening of the arteries causes it, or that the patient is just senile. Medical science is looking for the answer but more money is needed for research.

Imagine—learning that your loved one will progress from being forgetful, to total confusion, and in the final state of the disease will be demented—totally dependent for care, unable to control bodily functions, unable to eat or communicate, and totally disoriented, and will finally die physically long after the mind has ceased to funciton due to infection or other complication. This process called Alzheimer's is a slow one—8 to 12 years. During the course of the disease the family will exhaust their assets, their friends—no one wants to be around an Alzheimer's patient, and their emotional and physical health trying to manage a person who doesn't even know them anymore.

Imagine—the guilt when finally you must place your loved one in a nursing home, the pain when the nursing home calls and says they can no longer handle your loved one—he's too disruptive or dangerous to patients and staff.

Imagine—your only hope is that someone in the Alzheimer's Family Support Group will have had the same experiences and can help you. They will at least listen—there are no easy answers.

As professional advisor to the Erie Alzheimer's Family Support Group, I am concerned. Concerned that as our population ages and the number of Alzheimer's victims increases, will we have community resources for them? Day care, respite care, and more home health care are desperately needed already if we are to maintain these patients at home. What will the future bring? Four years ago when Saint Vincent Health Center became involved in the Alzheimer's Support Group there were a handful of family members. Now we have a mailing list of over 120, an average meeting attendance of 35, and have just applied to affiliate with National ADRDA [Alzheimer's Disease and Related Disorders Association]. We are trying to meet the needs of the Alzheimer's family but we need your help.

Mr. **Ridge**. I thank you very much for your testimony. I know from some previous correspondence and conversations that when you said imagine, that you were not imagining, that you have dealt with these on a day-to-day basis and the people with whom you work and share the responsibility and burden of Alzheimer's and that support group, so you were not imagining a thing. These are real people, real circumstances right here in Erie, PA.

Ms. **Lehman**. That is right.

Mr. **Ridge**. Thank you very much.

Mr. Carl Morschhauser is the husband of an Alzheimer's victim. I happened to know a couple of Mr. Morschhauser's sons a long time ago at Cathedral Prep, and I welcome you to this hearing, Mr. Morschhauser, and we will await your testimony.

STATEMENT OF CARL MORSCHHAUSER, RELATIVE OF ALZHEIMER'S VICTIM, ERIE, PA

Mr. **Morschhauser**. Thank you, Congressman Ridge and Congressman Lundine.

I wish to thank you for the opportunity of presenting my personal story to your committee as the husband of an Alzheimer's victim.

My wife, Janice, fell victim to a permanent, disabling illness known as Alzheimer's disease at the unusually young age of 52 in 1974. It was shortly after retiring from her job, that I noticed Janice became forgetful and began neglecting every day chores.

At first, her unusual behavior went unnoticed by me, but as the dementia developed, I had to notice certain behavioral changes. What was—what in the world was taking place in this wonderful woman I had married?

Within the next 2 years, it was obvious that Janice was undergoing a stressful change in both disposition and character. What was happening to her? What was taking place? Our life started to slowly change and the enjoyment of our favorite activities seemed to be lost.

Our relatives and friends seemed to notice the change and slowly started to withdraw their contacts with us as they realized they may be coping with a demented person. I began to feel lonely and had twinges of guilt as I struggled to maintain my patience and energy to see this helpless thing through and find out why it was happening.

I finally realized Janice was a victim of an unusual illness. I took her to a hospital where her son, who was a doctor, was able to supervise her diagnosis. After submitting to all types of tests and x rays and having ruled out any reversible problem, it was diagnosed that Janice had Alzheimer's disease.

Alzheimer's disease. What was that? How do we cure it? What procedures should we take to eliminate it? It was then that I was told the often terrible fact that Janice would never be a whole person again. She was 57 years old at the time.

I was told that constant attendance would have to be given to Janice for the rest of her life. Try to comprehend the thoughts racing through my mind for the next couple of years as I began to cope with the situation at hand.

Everywhere I went, I had to have Janice at my elbow so that even like going to the market, to the barber shop, to church, or to pay bills became very difficult. Not only for myself but for poor, confused Janice as well. Janice was unable to finish a sentence, let alone carry on any conversation.

At family gatherings, because of the disease, she was unable to express any emotion or compassion to either her children or grandchildren. Her most dominant emotion was fear of just being.

As my wife's premature dementia condition began to deteriorate and advance, I began to think more deeply about the future. I was now doing the routine chores that she had been handling, such as housekeeping, preparing meals, bathing her, dressing her, in addition to maintaining a full-time job. It was then that I had my heart attack and that phlebitis attack, which may have been caused by the stress placed on me by the situation.

God was good to me, as I realized He gave me back my health so I could keep going and take care of Janice. I tried to keep Janice at home with the assistance of paid help, but I knew when I was told that I would not be able to continue unless she had 24-hour care, which meant nursing home placement.

It was necessary to sell our home and start saving for the projected bills that would be coming. I had already been told that Medicare and other agencies disregard help or keep for any irreversible mental illnesses. Janice was just 59 years old when she entered the nursing home, and she is still there at the age of 64.

My nursing home bills are now in excess of $80,000. I am quite confident that with some assistance by the Federal Government, we care-givers could provide loving home care for these victims.

The Aging Committee must be aware there are thousands of families facing the horrible dilemma of providing adequate care for their loved ones afflicted with this dreaded disease. Yes, Alzheimer's disease has often been talked about as a silent epidemic. Yes, it is a silent epidemic as the afflicted person cannot speak out or communicate in any way to reveal their thoughts or emotions, which I can testify do prevail.

I look forward to seeing Janice every day because she does respond to me in some way in my presence, and I, in turn, feel it does make a difference in the quality of her life. Thank you.

[The prepared statement of Mr. Morschhauser follows:]

PREPARED STATEMENT OF CARL MORSCHHAUSER

I am writing to you as both a private citizen and as the President of the Northwest Pennsylvania Chapter of the Alzheimer's Family Support Group. Our Society is a Pennsylvania non-profit organization. The purpose of the Society is to assist persons who are afflicted with senility or degenerative brain diseases, and the families of these victims.

Senility is grossly misunderstood. It is not a natural process of aging, but is a degenerative brain disease with diagnosed pathology. There is no known cause for senility, nor is there a cure. This disease is not limited to the elderly. There are a significant number of persons who are afflicted with senility as early as the age of 40.

Dr. Butler of the National Institute of Aging has estimated that 1.5 million people in the United States suffer from senility. Many of these persons are eventually institutionalized in nursing homes. Dr. Butler has estimated the cost of nursing home care in 1980 to be $25 billion, and projects nursing home care to cost, by 1990, $75 billion.

This problem will dramatically increase because of the correlation between age and senility. It is estimated that one in every twenty persons, or 5 percent, of the population who reach the age of 65 suffers from senility; it is also estimate that one in every five persons, or 20 percent, of the persons suffering from senility in our area, including those under the age of 60, is 6,000. These are the people who are of concern to my local chapter.

I am also writing to you as an individual since my wife suffers from senility. My wife and I raised two boys and, through both of us working, were able to provide them both with college educations and, for one, medical school. We were settled into and experiencing the joys of "grandparenthood", with five beautiful grandchildren, when my wife's premature dementia condition began to manifest itself about eleven years ago.

She was only 52-years-old. In a few short years, her condition had deteriorated rapidly, to the point where previously routine functions, e.g., housekeeping, preparing meals, driving a car, bathing, dressing herself became impossible tasks. Today, at age 59, my wife would have trouble finishing a sentence for you, let along carrying on a conversation. At family gatherings, she is unable because of the disease to express any compassion or emotion either to her children or grandchildren. Probably the most dominant emotion displayed by her is fear * * * fear of being alone, fear of having to cope with the real world without me. That is another major consideration I ask you to ponder. Since my wife's illness, I have had to perform all functions required in maintaining a household, holding a full-time job, and caring at the same time for a "mental" invalid. I myself suffered a severe heart attack two years ago, which may or may not have been a result of the stress placed on me because of this situation.

Without the help and assistance, for which I and our society are asking, it is entirely possible that I also become incapacitated, thereby doubling the number of persons and the expenses to be borne by others. I am quite confident that, with some assistance provided by the federal government for victims of senility and their families, I would be able to provide loving home care for my wife for many years to come. Without that help, I don't believe that I can keep up the care I want to give. And, as the figures above indicate, there are thousands more faced with the same problem.

At this time there is very little assistance that is offered, to individuals suffering from senility and their families. Long-term health care is not part of the Medicare or Blue cross package of benefits. Home treatment and therapies are not included under medical insurance for persons suffering from senility. Medicaid provides some coverage to welfare recipients only.

As a member of the House Select Committee on Aging and the Subcommittee on Health and Long-Term Care, you are in an excellent position to help my wife and the thousands of others in your district who suffer from senility. I understand that you are keenly interested in this problem. I also understand you are preparing legislation that would give tax credits to children who build additions to, or modify, their home in order to take in an elderly parent or parents.

However, anticipating the specific provisions of any bill, I have a few comments I would like to state for your thoughtful consideration.

The bill should solve the problem of the vast majority of the senile population. There are many elderly persons who have no children, or have no children interested in their well-being. There are many elderly and/or senile persons who could be looked after in their children's homes, or in their own homes, if there were other services available, but the nonexistence or unavailability of services causes the institutionalization of senile individuals into nursing homes.

While a tax credit to children who house an elderly parent in their home is a useful alternative, it is not the only alternative, I suggest that it is but one of a list of things which the government can and must do.

I am familiar with Senate Bill 2809 that was sponsored in 1981. That bill would amend the Social Security Act by adding a title XXI for long-term health care for senior and disabled citizens. Besides calling for a limited tax credit for families caring for elderly dependent relatives, this bill would create the following necessary services which would keep the senile persons at home or out of a nursing home.

(1) Home health care services; (2) homemaker-home health aide services; (3) adult day services; and (4) respite services.

The proposal responds to a large number of needed services for victims of senility and their families. I wish to call your attention to the fact that Alzheimer's victims of senility cannot speak for themselves or petition Congresss as other groups do on calmoring for Government assistance, for one reason or another. It is up to we caretakers who have to carry their message and then hopefully with the help of Congress, the mental health will be resorted to this group of aging citizens.

This dread social and medical problem of senility is a growing national tragedy which requires the immediate attention of Congress. I ask for your help for myself, my wife, and for over 6,000 individuals who suffer from senility in Erie County and Northwestern Pennsylvania.

I would be happy to meet with you and other members of the House Committee on Aging. Perhaps forums or local hearings could be held in our area so your members may for themselves evaluate the needed services necessary for their afflicted constituents.

Mr. RIDGE. Mr. Morschhauser, thank you very much for your very pertinent and personal testimony. I am sure it was very difficult to share that experience with the audience and with the committee, and we are more appreciative of your willingness to do that for us.

I am going to initially turn it over to my colleague, Congressman Lundine, for some questions for the panelists.

Mr. **Lundine**. Before asking any questions, let me say that you have all made this disease, which we may have known about intellectually, very human and very real.

We had an outstanding person, with whom I am fairly well acquainted and also very well acquainted with his daughter and son-in-law, who was afflicted, and, so, I had some idea of what families go through, but you have made it so clear this morning, the personal dimensions and the human dimensions of this problem, that I want to thank all of you for your testimony. It really is excellent.

First of all, I would like to ask you, I guess, I should direct this to you, Ms. Lehman, but anybody else who wants to may add.

What conditions are there where Medicare and Medicaid benefits might be available to Alzheimer's disease patients, and what services are available to them under those Federal programs now?

Ms. **Lehman**. Medicaid and Medicare will help in the diagnostic procedures for the Alzheimer's patients. They will help pay for some of the history and physical, some of the lab work, the CAT scan. They will also pay for the periodic visits to the physician every 6 months to make sure the patient is not deteriorating.

After that point, the patient is custodial care, Medicare and Medicaid no longer pay for the Alzheimer's on-going care. We feel that this is an area that is in desperate need of help because family members need a respite, they need a break from the on-going care provided to the patient, and the present system, that is not available until the family has exhausted all of their assets, have sold their home, and have used that money to pay for the care of the Alzheimer's patient, and, then, Medicaid will kick in and start to pay for their care.

Mr. **Lundine**. Mr. Morrow, what do you think the appropriate Federal role should be in dealing with the disease?

Mr. **Morrow**. First of all, recognizing it as a problem that needs immediate attention, I fear that because Alzheimer's is so new and has grown so quickly, we have not the time to allow support groups to evolve over generations, as the American Cancer Society or perhaps the American Heart Association has taken generations to build support.

This disease is growing so quickly that we need action during the current generation, and we will need Federal support from that or for that to happen. Research is critical and community education also. It is such a misunderstood disease that the difficulty in providing care at any level, whether it be in the home with a family care-giver or in a facility, we, as professionals, need to learn a lot more about our families and the community.

We find victims are being shunned and abandoned out of frustration. We need an awful lot of community education, which is why I put that first on my list of things to do, and hope that that can start on the Federal level.

Research is certainly critical, and understanding that there are very complex needs, that there are no 2 days alike in the treatment of a patient, that a family needs support and the Federal funding which will allow home delivered services and adult day care to support a family as long as possible is also critically important. That Medicare does not pay for services, that Medicaid does not until a spend-down period occurs and a family has exhausted all of their resources, and that we have compounded problem on top of problem by adding financial burdens, emotional burdens, misunderstanding at the community level, abandonment, a number of secondary kind of problems that make the life of an Alzheimer's victim and the care provided by a family almost an impossible task.

Mr. LUNDINE. Well, granted that we should do every thing possible in terms of community education and research, in the area of treatment, do you think that there should be direct Federal funding through one of these programs where treatment, and, I gather, you think that home care or adult day care ought to be a part of the continuum of treatment?

How would you recommend that we try to fund that, given that we are dealing with limited Federal resources?

Mr. MORROW. Reimbursement, unfortunately, needs to be the key of that discussion. There are good support services available, but if they are unreimbursed, they will not grow and provide services. Because many Alzheimer's victims are not 65, they do not qualify for Medicare, and even those who are will not receive that benefit.

Reimbursement is the critical issue. We often find families coming to us so late in the progression of the disease that some of the preventitive kinds of support that might have helped them cope in the home setting, it is too late to turn back the clock at that point.

Early intervention, which, again, will require funding enough to allow it to happen, specifically, I have heard recommendations that perhaps the National Institute on Aging or some other recognized group on the Federal level might well be called on to channel funds for research and development of specialized programs, and to look specifically at the problem, and provide more detailed kinds of recommendations.

Mr. LUNDINE. Just one other question for you.

I presume that we are paying a lot of money right now, only it may have to be categorized. In other words, a lot of long-term care people who are on Medicaid probably are Alzheimer's patients, whether they are diagnosed that way or not.

Mr. MORROW. I suspect you would be amazed at the amount of money that is spent on a daily basis for the care of Alzheimer's patients.

Mr. LUNDINE. Ms. Paulson, I am interested in your observations, following just up on his comment before last.

Obviously, as in any disease, it is better if you can diagnose it early, and I would assume that your kind of a facility can provide a lot better services for a family the earlier in the diagnosis that they are able to identify it.

Is there any thing other than just general community education we could do to help with that early identification?

Ms. PAULSON. I do not know about any possibility of working with physicians in a kind of training, but I think from our own experience in our area, we have found medical care and diagnosis to be very inconsistent.

It is rare—it is more and more common now, but up until the last few years, it was a rare person who was actually diagnosed with Alzheimer's, and many physicians still refer patients to me with a diagnosis of hardening of the arteries or no diagnosis at all. They are considered to be "senile dementia."

I do feel that that is a problem. We have had people come from other areas where physicians were very in tune to working with people with dementia and from the very beginning were good about explaining to families what to anticipate.

In our area, I find often that physicians refer the families to me, and I feel they are really lacking in a lot of knowledge.

Mr. **Lundine**. One other agency, instead of the social fabric, that occurred to me while one of you were testifying, was the police officer. It would seem to me that there could occur an awful lot of seeming violations of law which are explainable only if one understands the disease.

Do any of you have any comment with regard to that aspect, and how we might deal with a better understanding of the problems resulting from people with Alzheimer's disease, acting in an unusual or bizarre fashion?

Ms. **Forhan**. The president of our chapter in Buffalo told us, about 2 years ago, that they are trying to train the policemen to recognize the difference between an Alzheimer's victim, let's say, to a drunk, but——

Mr. **Lundine**. Your point was that it is important to have policemen trained to understand the difference between an Alzheimer's patient and somebody who is drunk or somebody who is on drugs. We are putting an awful burden on a policeman who encounters somebody acting in an unsocial or unusual way to make that determination, it just struck me.

Ms. **Forhan**. Myself, in my group, I have asked my people to go to the police stations and explain, you know, the family way. If you see, would you come right away or at least if you see him in the street bring him back. We would be appreciative of that, you know. That is what I do in my group.

Mr. **Lundine**. That is——

Ms. **Lehman**. We also do that at our local support group. We encourage them to contact the police department if they notice that a patient is wandering and encourage them to bring them home. We have also had cards printed identifying the patient as an Alzheimer's victim so that if they would happen to have their wallet, the policeman would look in their wallet, they would see that they are a victim of Alzheimer's and the name and address would appear on this card.

Mr. **Lundine**. Once again, I want to thank all of you. You really have been excellent in describing this tragedy.

Mr. **Ridge**. Thank you.

Mr. Morschhauser, you provided some very revealing and personal testimony as to the impact of Alzheimer's on you personally and physically as well as upon you financially.

The idea that in order to meet the financial demands of care and treatment, you were put in a position to sell your home and make the other necessary financial adjustments is one that is very personal to you, but I have a sense, I am going to ask Ms. Lehman and Ms. Forhan to testify that it is not unique.

In this support group in which you—which you attend and which you work, are there other—have there been other personal circumstances similar to that, that has transpired? Other men and women had to make those kinds of sacrifices?

Mr. **Morschhauser**. Oh, yes. Sure. Sure. Quite a few in our area, in our immediate area, I might say, and how they handle it, of course, makes it pretty difficult.

I feel most fortunate. I have been able to handle it and give Janice the comfort that I have been able to provide for her, but there are many other families that I know have not had the means and have had to cope with it at home, which created quite a stressful situation for them.

It depends, of course, upon the support they would receive from their immediate family, but for those that do not have an immediate family, the pressures must be tremendous on them in trying to cope with this situation.

I just do not know how they could do it without help from the immediate family or friends, but, of course, friends are another thing when you cope with a situation, with the particular type of illness, it is very disturbing to any one to stay in contact with an Alzheimer's victim. There are so many unexplained things that happen or could happen that they just kind of divorce themselves from the situation as much as they can.

But, there are—I do feel sorry for a lot of families that have to cope with this within their own means and just cannot expand when the person is necessary to be sent to a nursing home, that they know they just cannot afford it.

Mr. **Ridge**. Ms. Lehman, would you care to comment?

Ms. **Lehman**. Yes; last Wednesday, when we had our support group meeting, Carl read his story, and I think the general consensus in the room was that everybody in the room could have written a very similar and very dramatic story that would have impressed you just as much as Carl's.

Alzheimer's stories are very tearful. There is nothing easy about it, and they all go through very similar circumstances, and I think that is the tragedy of Alzheimer's disease. What it does to the family.

Mr. **Ridge**. Ms. Forhan, you compare, I am sure. Would you care to make a statement?

Ms. **Forhan**. Yes, yes. I do absolutely. Right now, I have a case, a difficult one, it is a lady. Her—she wants to put her husband at a veterans' hospital. This has taken months. He is still home. She has sold her house, bought another place to be near her daughter, and she is almost broke. She is wondering what is going to happen to her. She does not have any means, let us say, if he should die. What is going to happen to me? That is why she has been crying.

She went from Westfield to Syracuse, NY, to consult with a lawyer, lawyers firm, and the fee was $3,500. So, I guess she came back, and told us all that. She was just a wreck, and she did not know where to turn. This is one case. She is scared to death. She cries. She says I am going to be in the street.

Now, I have another case where he was 52, stricken like that, just overnight——

Mr. **Ridge**. Fifty-two years of age was the victim?

Ms. **Lehman**. Yes; and he died at 54. Two years' time. They had no Social Security. The car was not paid. He had to go to a nursing home. He was a man about twice as tall as I was, and she just simply could not take care of that man, and when she did, it was not very competently, and she was just about starved.

Mr. **Ridge**. Thank you. Thank you.

Ms. Paulson, I wanted to ask you a couple of questions about adult day care and the kind of facilities that you operate.

Someone else, I think Marie-Theresa, mentioned that there are not any standards provided by the State government in terms of the adult care center in New York. Is my recollection correct?

Ms. **Forhan**. We have two respite rooms in the county.

Mr. **Ridge**. OK, OK. I am sorry.

Would you identify for me what kind, if any, of professional staff, first of all, that you have on duty that provides assistance and support in the course of your day care?

Ms. **Paulson**. First of all, adult day care in New York State does have some legislation; however, it only affects centers that are located in a long-term care facility, such as a nursing home. There are a number of free-standing facilities, which is what our center is—we are located in a church—and a center of that type is the one that has no regulations; we answer to nobody.

The staff we have currently consists of three full-time people, and I am really the only professional person on that staff. I am also assisted by volunteers and aides. We really scrounge to get staff. We also have people that are on work-relief programs, who are on public assistance. They have all been trained, and I am very confident that they do a very good job in caring for people, but I am very concerned about the lack of standards for adult day care.

We look at the standards that the National Institute on Adult Day Care has developed, but those are merely guidelines, and we try to live up to those, which is very difficult within the funding limitations we have.

Mr. **Ridge**. I suspect that because of the degenerative nature of the disease, there comes a point in time where you, as a professional, have to make the decision that the adult care facility that you are providing can no longer provide the treatment and the care for particular individuals.

I suspect it is very difficult at that point then to bring the family in, explain that you can no longer provide that service and look for an alternative form of care or treatment for them at that time.

Ms. **Paulson**. Well, actually, it is not, because usually it is the family who makes that decision. They are the ones that have much more burden for the care than we do, and it is usually at that point, if we are having trouble with the person, the family certainly is having trouble, and they will come to us for help. We have had many patients with Alzheimer's who have been in our facility for maybe a year or two, and then have gone into a nursing home, mainly because it was very difficult for the family to care for them.

Mr. **Ridge**. Thank you.

Mr. Morrow, to your knowledge, do long-term care institutions typically make distinctions in the type of care given to Alzheimer's disease patients from other patients?

Mr. **Morrow**. Typically, we would not. I am beginning to see a need for that, and I would suggest to you that a distinction should be made in the care because the care requirements are different. I find in our facility and others, I am sure, we are beginning to recognize that there needs to be a distinction. Alzheimer's patients are not typical geriatric patients who present themselves to us with organic brain syndrome or some other type of dementia.

One of the reasons why it appears to be, I think, a longer progression in younger people is that Alzheimer's is diagnosed later in the progress than the geriatric patient, and it goes undetected and passed off as some type of normal aging, which it is not.

But, I would suggest to you that the care of Alzheimer's patients should be very much unlike the care of other geriatric patients because of the need of the individuals and the families, the circumstances, the medical conditions and the progression of the disease, which require care that is more intensive.

Mr. **Ridge**. Well, recognizing that distinction as an administrator, you also recognize the impact of costs of the long-term care as it applies to the Alzheimer's victim.

In your judgment, do you believe that your colleagues exhibit discrimination, intentional or not, to the admission of Alzheimer's victims to their facilities?

Mr. **Morrow**. I suspect if it is not happening, it will soon because costs are difficult to isolate in the kinds of facilities that we run, which are based on levels of care. So that a patient who is requiring twice as much care as one in the bed next to him would still be paying the same. We do not have a selective kind of reimbursement system that allows us in Pennsylvania to allocate costs based on the type of care.

So, unfortunately, a reverse discrimination occurs against the other geriatric patients who end up paying for a much more intensive, specialized level of care in an all-inclusive per diem kind of rate. I think that that will need to be recognized and addressed, whether selective admission or deselective admission of Alzheimer's patients is the conclusion or whether it be a fairer type of reimbursement.

One of those two will come from that investigation. But yes it is a different kind of care, which will necessarily cost more.

Mr. **Ridge**. Thank you. I would just——

Ms. **Lehman**. I would like to comment on our experience with our support group related to that, that if the Alzheimer's patient is passive and a bed patient, then there is no difficulty in getting them into a nursing home. But if we have the aggressive patient or if he is a wanderer and will not stay confined to an area, then either they will be asked to find another facility or they will be denied admission, and then we have a great difficulty finding and helping the family members find some place to place that patient because of the level of care.

Mr. **Ridge**. Thank you.

Mr. **Morrow**. Which is where we begin to deal with philosophical kinds of differences between institutions and facilities in that should the management or treatment of the Alzheimer's patient be to subdue them through a medication program or drug therapy or should they be allowed to act out the course of the disease under unmedicated circumstances, which again creates a kind of care plan based on the philosophy of the facility, that makes the patients unlike each other from facility to facility.

Mr. RIDGE. I, too, would like to reiterate my colleague's thanks and appreciation for sharing your professional and personal stories and the contribution you have made to the hearing today.

We would like to take a recess now, to give every one a chance to stretch and get some coffee, and return to commence at 10:30. That will give us about 20 minutes.

Thank you very much.

[Brief recess.]

Mr. LUNDINE. The subcommittee hearing will come to order again, and I will again turn the moderating over to Congressman Ridge.

Mr. RIDGE. Thank you very much.

It was just brought to my attention that some of the literature we had provided about Alzheimer's disease may have been exhausted, given the number of people that are in attendance. We had some pamphlets and some other literature. If you care to get a package of that literature, please come up to us afterwards, and I will take your name and address and make sure that it is sent out to you, that you do receive a copy.

We do want to begin with our second panel. In the first panel, we tried to identify both professionally and personally the nature of the problem. The second panel, we would like to again lean on some personal but more often than not professional experiences in the response to that problem. We think we have three fine panelists to give us that overview.

The first witness will be Martha Fenchak Bell, who is president of the Alzheimer's Disease and Related Disorders Association of western Pennsylvania, who visits us this morning, I believe, from West Mifflin. Very good.

Mr. LUNDINE. Before Ms. Bell begins, just one thought that I had before I forget it, because I forget.

I—first of all, all of your testimony will be made a part of the record, and if you can summarize, that would be appreciated. And, second, I would ask for unanimous consent that such additional testimony as is presented to Congressman Ridge on behalf of other people that were not able to testify here, and that we agree needs to be made a part of the record, will be made a part of the written record.

Without objection, that will be done, and should any one have to discuss that, you may do that with the staff or one of us afterwards.

Thank you very much. I am sorry for the interruption, Ms. Bell.

STATEMENT OF MARTHA FENCHAK BELL, PRESIDENT, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION OF WESTERN PENNSYLVANIA, WEST MIFFLIN, PA

Ms. **Bell**. Thank you. I would like to thank this honorable committee and Congressman Ridge and Congressman Lundine for the opportunity to share with you the tragic plight of your constituents suffering with Alzheimer's disease or a related disorder.

Right now, as we said before, over 3 million Americans and 200,000 Pennsylvanians are afflicted as well as their families. I was privileged to cofound the National Alzheimer's Disease and Related Disorders Association in 1979, and the Chronic Organic Brain Syndrome Society of Pennsylvania the year before.

I am presently founder and president of ADRDA of western Pennsylvania, and a third generation at risk Alzheimer's disease person with my maternal grandmother, my mother, and my mother's brother all dead because of this disease.

As I walked around the auditorium and the Atrium today, I do not want to forget the people who cannot be with us, wives and husbands, sons and daughters, who are too tired, too sick, and too discouraged. They worry that the care will get to be too much, the cost will be too high, the vigil will be too long, and the cure too far away, and they despair.

I see before me faces, often at the oddest times. They are the bewildered faces of Alzheimer's patients. June, standing next to me at a recent birthday party, saying: "Why is it that Alzheimer's disease has to hit you, even if you have tried to do good all your life," and Paul saying: "I am going to lick this problem within my head, I just need some time." Then, there are other victims who cannot verbalize their pain, but you can see it, you can see it in their eyes.

Just ask Terry, one of our family members, if she feels that Tom knows things and understands them. My own mother would look at me with her eyes and her face would soften as I sat beside her, and it was as if she was comforting me. I have seen Merle as she struggles to help Steve down the steps and get him to day care. She is tired, so very tired.

I wonder who will die first. I heard families talk in apologies for the type of care the patient gets in an institution; the bed sores that they are afraid to ask about; the hot meal that never gets served unless the families are there to do it; the fear that families have of losing a bed because they are on Medicaid.

I have a hospital bill in my hand that reads $356,221.18 for Martha Rita Ruschak, because her family refused a room in a nursing home that was unheated in the dead of January, and that home was notorious for poor care. Consequently, no other beds opened in the city to admit this patient.

So, if a bed opens in the city, you better run and take it or pay the price. Never mind if you cannot sleep at nights, never mind if it is a death sentence because, after all, Alzheimer's disease is an incurable illness, so what is the big deal.

The big deal is that in this land of Live-Aid, Farm-Aid, catastrophic accident insurance, there is nothing short of welfare in the form of Medicaid for the Alzheimer's and related disorder patients and families. Families who have been self-sufficient are now scrambling to get on Medicaid by divesting themselves of what little savings they have to get under the $1,500 asset level.

Where are the people that we are allowing this to happen? We are the only country besides South Africa that does not have some form of socialized medical care. I want to refer briefly to remarks that I have in my written testimony.

On page 11, as a direct suggestion for Federal legislation, I believe that we need to recognize that the continuum of care of the needs of the Alzheimer's patients, depending upon the state of affliction as the disease progresses, and the mental and physical function abilities decrease, must be used. We need to look at perhaps a suggestion of a Medicare Part C insurance reimbursement that could be constructed as an insurance program, financed through FICA taxes. It would be understood that this program would have an annual deductible and some coverage requiring copayment.

However, it should be drafted in such a way perhaps to encourage private health supplemental insurance, such as is presently with Medicare Part A, so that families can also contribute up to a reasonable amount.

The second area that I would like to see addressed is some sort of national catastrophic health insurance, so that this program could act as a safety net to the inexhaustable cost of long-term care.

So, if a family crosses—the patient care exceeds something like $50,000, that the Federal Government could step in and pay the costs thereafter in full. This, too, could be a program that would encourage reasonable family expenditures and private insurance involvement.

Unlike Medicare Parts A and B which is universal, only a small segment of the population would have to resort to the proposed Federal long-term care programs, so the demand would be finite, but we would be looking at at least a step, a solvable way of addressing this dilemma.

So, unless we address some sort of comprehensive long-term health care coverage and we look at appropriate services for the patients now, what we are looking at, generally, is the barrel of a shotgun, and we may as well, as a nation, pull the trigger because we are going to see families doing that and society turning off care in general.

I have testified before numerous State and Federal committees over the last 5 years. Please make my plea before your committee the spark that will at last light the flame for justice and quality for these devastated families and their patients. Thank you.

[The prepared statement of Ms. Bell follows:]

PREPARED STATEMENT OF MARTHA FENCHAK BELL, PRESIDENT, ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION OF WESTERN PENNSYLVANIA

On behalf of Alzheimer's Disease and Related Disorders Association of Western Pennsylvania, I appreciate the opportunity to testify on behalf of the some 2 million Americans tragically suffering the affliction collectively represented by our national organization and its local chapters and affiliates.

I am a cofounder and former vice president of the national Alzheimer's Disease and Related Disorders Association. Previously, in 1978, I was the founder of the Chronic Organic Brain Syndrome Society which evolved into A.D.R.D.A. of Western

Pennsylvania. My maternal grandmother, maternal uncle, and my mother all suffered from Alzheimer's disease.

Today, I ask two questions of the subcommittee for its consideration:

(1) Does the subcommittee agree that our loved ones who are cruelly afflicted with Alzheimer's disease deserve to be treated with dignity and receive quality care at appropriate levels of long-term care?

(2) Does the subcommittee agree that the appropriate long-term care, and reimbursement for its costs, is a public responsibility of the Government of the United States?

A. THE EXISTING REALITIES OF LONG-TERM CARE

The estimated 2 million Americans afflicted with Alzheimer's disease and their families, most of whom are or have been taxpaying and voting citizens of our country, are undergoing intolerable suffering because of the neglect of both political parties in Congress to the critical need for long-term care. On behalf of our loved ones, I raise the question of human justice for them who, through no fault of their own, become wholly incapacitated by a nefarioius disease of no known cause or cure.

No matter how physically and cognitively debilitated our loved ones become, they are still human beings who are alive and deserve necessary care to enhance their dignity and ease their suffering.

Our valiant families, who struggle to provide care for our loved ones at home and who place them in personal care homes, nursing homes, and State psychiatric hospitals only as a final and necessary resort, are destroyed by the extreme physical, emotional and financial burden engendered by the malevolent curse of senile dementia.

The present long-term health care system in America is wholly irrational and insensitive as it fails to comprehend the victim's actual needs and emphasizes payment throuigh the medical programs of public welfare for nursing home care only.

From the time of disgnosis, our loved ones will live on an average, for a period of 5 to 15 years. The patient does not immediately change from a condition of perfect health to a condition of total physical and intellectual incapacity. As our loved ones pass through the different stages of the disease process, they require different levels of care. In the home of a caring family, the victim generally does not require institutional care for several years.

The problem in our country is that the only third-party reimbursement available to patients and families is through the general welfare programs of Medicaid and medical assistance, and these programs primarily pay for care in a nursing home or State hospital.

Except in a few cases and for limited periods of time, Medicare and the Medicare supplement insurance programs offered by Blue Cross and other private health insurers, do not pay for home care equipment and services, personal/residential care homes, or nursing homes. Further, a victim or potential victim cannot insure himself against the catastrophic costs of long-term care and irreversible illness.

The ultimate resort to the medical welfare programs occur in one of two ways: either the patient actually bankrupts himself and his spouse through the actual payment or charges for necessary service or equipment; or the patient artifically bankrupts himself by transferring his assets two years prior to applying for medical assistance. Resort to the medical welfare programs causes premature institutionalization through their payments to nursing homes, and is irrational when there exists less expensive alternatives for much of the time of the disease process during the long-term care continuum.

However, resort to the medical assistance program does not solve care problems for our loved ones and their families. Adequacy of care in nursing homes is highly uneven because of regulations requiring that only minimum standards be met and because state enforcement is often less than strict. The problem of adequacy of care is intensified because of the amount of reimbursement to nursing homes is insufficient under Medicaid. It does not take a Ph.D. in economics to understand that if the average nursing home daily charge is $65 per day, and Medicaid pays $44.50 per day, one of two results occur. Either nursing homes will not accept medical assistance patients, or assistance patients do not receive the same quality of care as private pay patients. Indeed, a fair number of good nursing homes no longer accept medical assistance patients on any basis or time.

Accordingly, the number of options in nursing home placement becomes quite limited for our loved ones and families, and this is especially devastating to families who have exhausted their resources prior to resort to Medical Assistance when it is determined that the nursing home willing to accept their loved one is less than satisfactory for their loved one's needs.

Our loved ones and their families are not "welfare bums" nor are they cynical or insensitive individuals who cavalierly dump their loved ones into nursing homes at the public's expense. Our loved ones and families are frustrated individuals who live a continuing nightmare without help from societal institutions. Our families do not want to resort to welfare, but it becomes a resource available in financial desperation.

Our families damn the existing and injust governmental system in which the needs of long-term care patients are ignored, and which reduces a formerly self-sustaining person to a public charge through no fault of his own.

B. LONG-TERM CARE AND THE SOURCES FOR FUNDING OF REIMBURSEMENT

1. Defining "long-term" care.—In order to attain reimbursement for the catastrophic costs of Alzheimer's disease and the related disorders, the subcommittee needs to define what is meant by "long-term care."

Some policy makers describe "long-term care" only as institutional care in nursing homes and mental institutions. I suggest that this definition is not only restrictive, but does not consider the total need and best interest of the patient.

We are all aware that an Alzheimer's victim, unlike a stroke patient, is not immediately rendered totally incompetent by the onset or "attack" of the disease. However, I suggest that some governmental policy makers are still not apprised of the slowly progressive deterioration of mind and body which the dementia patient suffers. Therefore, long-term care needs to be defined for policy makers that takes into consideration the different needs of the patient at various points in the disease process.

I would suggest that the "long-term" care needs to be defined by the model of a "continuum of long-term care" in which the victim's needs, and the family's needs, increase during the term of the affliction. Further, that the patient requires services from not only medical professionals, but of professionals of other disciplines and of semi-skilled individuals. Finally, the patient has need of medical and non-medical equipment and supplies for care both in-home and in places which provide long-term care.

My description of a long-term care continuum is as follows:

(1) In-home care.

(a) Respite companions; (b) homemaker-home health aides; (c) visiting nurses; (d) equipment, such as: hospital bed; lifts; wheelchair; step-elevator; physical therapy equipment; etc.; and (e) supplies, such as: incontinence pads; diapers; special dinnerware and utensils; etc.

(2) Adult day care centers—self-explanatory.

(3) "Institutional respite"—to provide temporary placement in an appropriate facility during family crises or major family events, or to provide a temporary "vacation break".

(4) Personal care or residential care home—provides an intermediate point of nursing care between "in-home" and skilled nursing care for the Alzheimer's patient.

(5) Nursing home care—for those who require skilled nursing care or whose care requirements are greater than can be rendered in-home or at the residential care home level.

(6) Mental health care—for those whose behavioral condition is such that they require long-term institutional mental health care, or periodic mental health treatment.

(7) Hospice—for those who are in the end-stages of the disease process, although their prognosis may be greater than 6 months.

The long-term continuum describes different levels of care and services for different stages of the disease process which affect the patient, and is proposed as a rational method to determine reimbursement for the progressive and necessary medical and nonmedical needs of our loved ones.

I strongly advocate the use of a long-term care continuum in order to educate and guide policy makers. Without such a model, we might get a program which pays only for nursing home care, which would cause the unfortunate result of premature institutionalization of our loved ones. Or, we might get a program which pays for all services except nursing home care, through a governmental proposal for cutting nursing home costs by shifting the burden of care solely to the patient's home. This latter theory would not alleviate the family burden of cost for the most expensive and frequently necessary aspect of long-term care.

Therefore, I suggest that the definition of long-term care, as exemplified by the outline of the long-term care continuum, provides a comprehensive and rational definition of the patient's needs and requirements.

II. What is the family's responsibility?—In terms of advocating for long-term care cost reimbursement, the question arises as to whether the patient and family should bear any of the expense, and if so, then to what extent?

Until the rise of the social welfare programs under the New Deal, and successor Federal programs, the family was considered to be the primary source of support for an indigent relative.

Beginning with Queen Elizabeth's Poor Law of 1598, England and its American colonies imposed criminal sanctions on family members for failure to support a relative in financial need. In Pennsylvania, for example, the family responsibility once extended reciprocally in the family tree from grandparents to grandchildren.

Strong vestiges of family responsibility still remain as the pre-Welfare family responsibility laws still exist in many States, and a number of State Welfare/Medicaid programs mandate family contributions to help defray the expense of the state support.

Indeed, there is an attitude on the part of some policy makers that payment for long-term care should be a family responsibility. This is the result of two still common misconceptions of long-term care:

(1) That the family does not care about their aged and sick parents and seeks to dump them into nursing homes at their earliest opportunity; and

(2) That most nursing home patients don't need to be institutionalized.

The reality is that due to better medical care, the chronically ill live longer, and that the aggregate costs of nursing home and other long-term care services are prohibitive to the average American family.

It is unconscionable for government to expect the patient, his spouse, and family to expend a minimum of $50,000 to $100,000 for necessary long-term care. Therefore, the family cannot be considered a sole or primary source for long-term care costs.

III. What should be the responsibility of the Federal Government?—The Federal Government is responsible for national problems, and long-term care is a national problem.

Beginning with the New Deal, the Federal Government has responded to the needs of its citizens who are dependent. For example, Social Security and Medicare are government insurance programs to aid the elderly. Other Federal programs exist to aid infants, the disabled and the poor.

The conservative fiscal policies of the Reagan Administration have tightened entitlement and payment amounts of Federal social welfare benefits. However, the continuing existence of these programs has not been challenged. Thus, even a conservative administration has recognized a continuing duty on the part of the Federal Government to provide aid to those who cannot care for themselves.

Moreover, Senator Robert Dole, a leading fiscal spokesman, has publicly stated his interest in reimbursement for long-term care costs.

Finally, we should remember that, except for the Union of South Africa, the United States is the only industrialized western nation which does not have national insurance for long-term care.

Therefore, the Federal Government does have the responsibility to be the sole or primary insurer for the cost of long-term care, and that an interest does exist for this issue by leading legislators of both political parties.

IV. Is there a State government responsibility for reimbursement of long-term care costs?—With the present efforts of the Reagan Administration for reducing Federal Government involvement, some political theorists suggest a trend that State government will assume a greater responsibility for social welfare programs under the popular theory of "local" control.

Some responsibility for reimbursement of long-term care costs is already assumed by the states through their participation and administration of Medicaid/Medical Assistance Programs.

Therefore, State Government could assume greater responsibility for funding long-term costs for its citizens, although a State approach, in lieu of a Federal approach, is more hazardous because of a lack of uniformity of reimbursement amounts and entitlements among the states.

V. General availability of private long-term care insurance as the panacea?—Private insurance could and should have a role for reimbursement of long-care costs. Private insurance provides an attractive alternative as it would be nongovernmental, competitive, and avoid political questions of tax increases, governmental spending, and creation of governmental bureaucracies. However, resort to private insurance raises the following questions:

(1) Whether private insurance coverage would be satisfactory for the patient's long-term care needs?

(2) Whether private insurance programs would be maintained if policy sales were unsatisfactory or the cost of claims too expensive?

(3) Whether such insurance would be available and affordable by the poor?

(4) Whether private insurance would insure our loved ones who have "pre-existing conditions"?

Therefore, should private insurance have the sole responsibility, the primary responsibility, or a supplemental responsibility, for long-term care costs.

I suggest that private insurance would not afford universally accessible long-term care insurance, so that the basic solution resides with government insurance. However, this does not mean that advocacy efforts among private insurers should be neglected. Private insurance does have a role to play, but it should not be considered a panacea.

VI. What about medical welfare benefits?—If universal public long-term care insurance becomes available, than the need for medical welfare insurance would no longer exist. However, so long as long-term care insurance is not universal, the there will be a need to seek reform of the existing Medicaid/Medical Assistance laws and regulations for the benefit of its recipients.

My testimony is concerned solely with attaining non-welfare third-party reimbursement for all of our patients as the total solution. Therefore, no discussion of medical/welfare reform is included here.

C. SUGGESTIONS FOR FEDERAL LEGISLATION

In general, I believe that government insurance programs should consist of the following parts:

(1) A recognition of the continuum of needs of the Alzheimer's patient depending upon his stage of affliction in the disease process and his mental and physical functioning abilities.

(2) That reimbursement be keyed to the patient's needs resulting from his mental and physical functioning abilities.

(3) That the rate of reimbursement accurately reflect the real cost of "goods" and services necessary for the patient at his mental and physical functioning ability and condition.

(4) That the insurance should be universal.

I. Medicare "part C".—I suggest that Medicare be expanded to include a "Part C" for long-term care reimbursement. This would be constructed as an insurance program to be financed through increased F.I.C.A. taxes. It would be understood that such an insurance program would have an annual deductible and some coverage requiring co-payment. However, it could be drafted in such a way as to encourage private health supplement insurance such as exists presently with Medicare, part A, or to encourage reasonable private contribution from the patient, spouse and family.

II. National catastrophic health insurance.—I suggest that this proposed program could act as a safety net to the inexhaustible cost of long-term care. If the payment for costs of long-term care of a patient exceeds a certain amount, such as $50,000, then the Federal Government would step in and pay the costs thereafter in full. This, too, could be a program which would encourage reasonable family expenditures and private insurance involvement. Also, unlike Medicare part C, there would be no age threshold for entitlement. This program would also be funded through F.I.C.A. or another income tax.

Unlike Medicare, parts A and B, which is universal, only a small segment of the population would have to resort to these proposed Federal long-term care problems. Accordingly, the demand would be finite. Also, resort to these programs would alleviate some the Federal expenditures for Medicaid, so that the burden to the treasury may not be severe.

D. CONCLUSION—LONG-TERM CARE REIMBURSEMENT AS A MORAL IMPERATIVE

In an era of fiscal austerity and rising health care costs, selling Government and private health insurers on catastrophic care will be a difficult task.

Potentially, we have the numbers of family members and health care service providers to implement effective political and consumer pressure.

More importantly, this issue is a moral imperative, touching on a simple question of human justice and decency for those who, through no fault of their own, are savagely afflicted in mind and body by a disease of unknown cause or cure.

Apart from the Union of South Africa, ours is the only nation which waffles on the question as to whether long-term health care, and access thereto, is a fundamental human right. Access to, and meaningful reimbursement for necessary and quality long-term care services cannot continue to be considered a privilege, but must be considered a necessity and a right. Therefore, I suggest that the ultimate goal should be a universal public long-term care insurance, rationally determined for the actual needs of the patient.

Mr. RIDGE. Thank you very much.

We are going to employ the same procedure as we did before. I would like to listen to all of the panelists before my colleague and I ask some questions.

I would now like to introduce to you Barry D. Lebowitz, Ph.D., Acting Chief of the Mental Disorders of the Aging Branch, National Institute of Mental Health, Alcohol, Drug Abuse and Mental Health Administration, and I want to thank you, personally thank you for taking the time to come up today and for the commitment that you have shown, the leadership you have shown in this particular area. Doctor?

STATEMENT OF DR. BARRY LEBOWITZ, NATIONAL INSTITUTE OF MENTAL HEALTH, AGING BRANCH, ROCKVILLE, MD

Dr. LEBOWITZ. Thank you. I am pleased to testify before the Subcommittee on Health and Long-Term Care and the Select Committee on Aging.

In my statement today, Mr. Chairman, I am going to try to convey a sense of the scientific and clinical excitement that is building around the issues of Alzheimer's disease.

This research is of a major programmatic priority in the Department of Health and Human Services, where a department-wide task force was established in 1983. The first report of that task force was issued in the fall of 1984, and its work continues in the coordination of the departmental effort.

Until recently, this major disease was neglected or the characteristic features were attributed to the normal experiences of growing old. Older people were considered to be senile and their disabilities were seen as inevitable.

We now know much better, Mr. Chairman. We realize that this is a disease of widespread prevalence afflicting 1 in 20 of the over-55 population, and 1 in 5 of the over-85. With projections of the rapid growth of the 85+ population, we are confronting a problem of epidemic proportion.

We are all encouraged by recent scientific information which suggests that this disorder does not have to be perceived with the stark, utter pessimism that heretofore has characterized it. Much remains unknown, but the support for scientific efforts has begun to prove fruitful.

Overall, Public Health Service research in our own laboratories and in grants and contracts for the scientists in the field have quadrupled since 1981. Last year, nearly $50 million was spent on these studies. When this is added to the major commitment for support of research in the neuro-sciences, in general, the combined effort is substantial and significant.

In my remaining time, I would like to highlight five areas of this research effort and to focus on the directions in which all of us are moving.

One major area of study will help us much better identify the disorder, and characterize its stages. Much of this research is using the very newest of the exciting technologies now available for biomedical investigations.

Positron emission tomography, CAT scan, and magnetic resonance imaging, are being used to systematically study the structure and operation of the brain while new chemical techniques are being used to carry out innovative biochemical analyses of brain tissue and fluid of live patients.

Psychometric studies are being used to develop earlier and more sensitive characterizations of the behavioral dimensions that we have heard about this morning. This important work will some day lead us to a definitive diagnostic marker for the disease in live patients, something that we do not now have.

The second important area of research is directed toward identification of the subtypes of the disease. It is clear to most investigators that Alzheimer's is not a single entity, but at this point, only very preliminary classifications can be made.

Age of onset appears to be critical, with the early onset form of the disorder showing consistent differences when compared with the later onset form. In addition, there is much attention being paid to genetic issues in the disease, where there is a search for those factors that might be used to identify a familial form of Alzheimer's disease.

These studies are interesting in another light as well, for a strong association has been shown between Down's syndrome, the most common form of mental retardation, and Alzheimer's disease, in that all Down's victims who live to about age 45 develop the characteristic placques and tangles that are in the neuropathologic signs of the disease.

We know that Down's syndrome is a chromosomal abnormality, and we, therefore, may have an important piece of the picture for Alzheimer's disease in this finding.

These genetic studies along with studies of viruses, toxins, immune-system disfunctions, and other models, are all geared toward uncovering clues to the origin and to the cause of the disease.

At the same time, research for an effective treatment to reverse or slow the course of the disease is proceeding aggressively. It is only in the last decade that scientists have pinpointed one of the major characteristics of Alzheimer's disease, namely a loss of acetylcholine, one of the brain's chemical messengers or neurotransmitters, that allows information to travel within the brain between the neurons.

In a significant series of studies to document what is now called the cholinergic hypothesis, the nature of that chemical loss has been detailed and the region of the brain responsible has been identified. Pharmacologic trials aimed at enhancing cholinergic functions of the brain have shown limited positive results in a few patients for relatively short periods of time.

These provide the basis for optimism, however, not in identifying treatment, but at least in showing that the disease is modifiable and is not an inexorably declining phenomenon.

Although the cholinergic system is always involved in Alzheimer's disease, research is now directed toward identifying other neurotransmitters that may also be involved. These studies will lead to the development of combinations or multiple neurotransmitter approaches to therapy.

In addition, new techniques of drug delivery are being examined, many of which involve neurosurgical procedures and the implantation of pumps to deliver chemicals directly to the brain. Such studies are highly exploratory at this point, though preliminary results have shown that the techniques may, in fact, be feasible and could provide an important technology for the delivery of new drugs as they develop.

While studies directed at the causes of the disease and treatments are proceeding, it is important to direct research to management of the many kinds of behaviorial, emotional, and cognitive symptoms you have been hearing about this morning.

The great majority of Alzheimer's victims reside in home settings with care provided by family members. The problems of wandering, sleeplessness, agitation, suspicion, depression, disorientation, and others that we heard this morning can and do provide major strains for the families and tax caring family members beyond their capacity to cope and to provide effective care.

An important area of research is to develop new approaches to this full range of problems. Such studies are often medical, that is the identification and treatment of co-existing physical and psychiatric conditions, and in the identification of potential side effects of medication or of misuse of medication. Psychological, environmental and social research is directed at many of these problems, and effective interventions have been developed in many of these areas.

Even with the best of what is available from all these studies, families are under tremendous strain in providing care on a continual, round the clock basis. Several research investigators have focused their attention on these families and on the stress and burden associated with the care.

These studies have begun to identify the types of supportive intervention that can be used by families along with counselling and other support useful in addressing many of the problems experienced by those who care for persons with the disease.

The cycle of frustration, anger, guilt, burn-out so often discussed by those this morning is only a small part of the heroic public service being accomplished by these caring people, and researchers and clinicians have recognized that they can assist with this feeling through a variety of supportive intervention.

I want to conclude, therefore, on an optimistic note. Research in Alzheimer's disease has grown substantially and in the last few years we have seen important new developments in knowledge.

The investigators for many disciplines are bringing the strength of their perspectives to this area. At the national level, the collegial and collaborative relationships among the research institutes are firm and productive with jointly issued announcements soliciting research and joint consideration of funding issues.

The Department-wide task force on Alzheimer's disease continues its coordinating role and last spring sponsored a national conference bringing together families and research investigators to help set the research agenda for Alzheimer's.

Mr. Chairman, I thank you for the opportunity of testifying on research efforts in Alzheimer's disease, and I will be pleased to answer any questions that you may have.

[The prepared statement of Dr. Lebowitz follows:]

PREPARED STATEMENT OF BARRY D. LEBOWITZ, PH.D., ACTING CHIEF, MENTAL DISORDERS OF THE AGING BRANCH, NATIONAL INSTITUTE OF MENTAL HEALTH, ALCOHOL, DRUG ABUSE, AND MENTAL HEALTH ADMINISTRATION

I am pleased to testify before the Subcommittee on Health and Long Term Care of the Select Committee on Aging.

In my statement today, Mr. Chairman, I am going to try to convey a sense of the scientific and clinical excitement that is building around issues in Alzheimer's disease. This research is of major programmatic priority in the Department of Health and Human Services where a Department-wide task force was established in 1983. The first report of that task force was issued in Fall 1984, and its work continues in the coordination of Departmental efforts.

Alzheimer's disease has come to be recognized as a major public health program both in our Nation and in the world. There are over 2 million older Americans afflicted with this disorder, a progressively deteriorating brain disorder of unknown cause. Victims of Alzheimer's disease account for approximately half the occupants of nursing home beds in our Nation, and there are at least twice as many victims outside institutional settings being cared for by their families.

It is characteristic of this disorder that patients will exhibit problems of the following types:

Cognition, with increasingly serious difficulties in memory, orientation, and intellectual function;

Emotion, with often severe accompanying depression or delusions;

Behavior, with characteristic agitation, wandering, and sleeplessness; and

Psychosocial function, with progressively greater likelihood of family stress and caregiver burnout.

Until recently, this major disease was neglected or these losses were attributed to the normal experiences of growing old; older people were considered to be senile, and these losses and disabilities were seen as inevitable.

We now know better, Mr. Chairman. We realize that this is a disease of widespread prevalence afflicting one in twenty of the over 65 population and one in five of the over 85 population. With projections of the rapid growth of the 85-plus population, we are confronting a problem of epidemic proportion.

In the long-range, our objectives for research are to develop more effective ways of characterizing the disorder and its subtypes, to identify the causes, and to develop effective treatment and prevention strategies.

In the short run, out objectives are to reduce excess disability and maximize individual functional level and family coping through developments of behavioral treatments, family supportive interventions, and models of family, community, and institutional care.

We are encouraged by recent scientific information which suggests that this disorder does not have to be perceived with the stark and utter pessimism that heretofore has characterized it.

Much remains unknown, but the support for scientific efforts has begun to prove fruitful. Overall, Public Health Service research in our own laboratories and in grants and contracts made to scientists in the field has quadrupled since 1981; last year nearly $50 million was spent on these studies. When this is added to the major commitment for support for research in the neurosciences, the combined effort is substantial and significant.

In my remaining time, I would like to highlight five areas of this research effort and to focus on the directions in which we are moving.

One major area of study will help us better identify the disorder and characterize its stages. Much of this research is using the very newest of the exciting technologies available for biomedical investigation: positron emission tomography and magnetic resonance imaging are being used to systematically study the structure and operation of the brain while new monoclonal antibody techniques and chromatography approaches are being used to carry out innovative biochemical analyses of brain tissue and fluid in Alzheimer's disease. Psychometric studies are being used to develop earlier and more sensitive characterizations of the behavioral dimensions of the disease.

This important work will someday lead us to a definitive diagnostic marker for Alzheimer's disease in live patients; at this point the diagnosis can be made definitive only after death through post-mortem examination of brain tissue to identify the characteristic plaques and tangles of the disorder. In the absence of a diagnostic marker in living patients, the diagnosis must remain uncertain and is based upon exclusion of other possible coexisting conditions; this leaves room for error, and even in the best of centers, a diagnostic error rate of 10 to 20 percent is not uncommon. This is clearly an area in which substantial work must continue to be pursued.

A second important area of research is directed toward identification of subtypes of the disease. It is clear to most investigators that Alzheimer's is not a single entity, though at this point only very preliminary classifications can be made. Age of onset appears to be a critical component, with the early-onset form of the disorder showing consistent differences when compared with the later onset form. In addition, there is much attention being paid to genetic issues in the disease where there is a search for those factors that might be used to identify a familial form of Alzheimer's. These studies are interesting in another light as well, for a strong association has been shown between Down's syndrome (the most common form of mental retardation) and Alzheimer's disease in that all Down's victims who live to about age 45 develop plaques and tangles that are the neuropathologic signs of Alzheimer's disease. We know that Down's syndrome is a chromosomal abnormality, and we may therefore have an important piece of the picture for Alzheimer's disease in this finding.

These genetic studies, along with studies of viruses, toxins, immune system dysfunctions, and other models, are all geared toward uncovering clues to the origin and cause of the disease.

At the same time, the search for an effective treatment to reverse or slow the course of the disease is proceeding aggressively. It is only in the last decade that scientists have pinpointed one of the major characteristics of Alzheimer's disease, namely, a loss of acetylcholine, one of the brain's chemical messengers or neurotransmitters that allows information to travel between neurons. In a significant series of studies to document what is now called the "cholinergic" hypothesis, the nature of the chemical loss has been detailed and the region of the brain responsible has been identified. Pharmacologic trials aimed at enhancing cholinergic function in the brain have shown limited positive results in a few patients for a relatively short time. These provide the basis for optimism, however, not in identifying a treatment but in showing that the disease is modifiable.

Although the cholinergic system is always involved in Alzheimer's disease, research is now directed toward identifying other neurotransmitter systems that may be involved. These studies will lead to the development of combination or multiple neurotransmitter approaches. In addition, new techniques of drug delivery are being examined, many of which involve neurosurgical procedures and implanting of a pump to deliver chemicals directly to the brain. Such studies are highly exploratory at this point, though preliminary results have shown that the techniques may be feasible and, therefore, could provide an important technology for the delivery of new drugs as they are developed.

While studies directed to the cause of the disease and to treatment are proceeding it is also important to direct research to management of many of the behavioral, emotional, and cognitive symptoms characteristic of Alzheimer's disease. The great majority of Alzheimer's disease victims reside in a home setting with care provided by a family member. The problems such as wandering, sleeplessness, agitation, suspicion, depression, disorientation, incontinence, etc. can and do provide major strain for the family and tax caring family members beyond their capacity to cope and to provide effective care. An important area of research is the development of approaches to address this full range of problems. Such studies are often medical, that is, in the identification and treatment of coexisting physical and psychiatric conditions and in the identification of potential side-effects of medications or of mixtures of medications. Psychological, environmental, and social research is also directed at many of these problems and effective interventions have been developed in many areas. The focus of much of this research is on maintenance of optimal functioning and the reduction of what has come to be called "excess disability," that is, the circumstance in which the functional level of the individual is substantially below what would be expected strictly on the basis of the severity of the Alzheimer's disease itself.

Even with the best of what is available from all these studies, families are under tremendous strain in providing care on a continual, round-the-clock basis. Several research investigators have focused their attention on these families and on the stress and burden associated with care. These studies have begun to identify the types of supportive interventions which can be used by families along with the counseling and other support useful in addressing many of the problems experienced by those who care for persons with Alzheimer's disease. The cycle of frustration, anger, guilt, and burnout so often discussed by those who provide care is only a small part of the heroic public service being accomplished by these caring people, and researchers and clinicians have recognized that they can assist with these feelings through a variety of supportive interventions.

I want to conclude, therefore, on an optimistic note. Research in Alzheimer's disease has grown substantially and in the last few years we have seen important new developments in knowledge. Investigators from many disciplines are bringing the strengths of their perspectives to this area. At the National level, the collegial and collaborative relationships among the research institutes are firm and productive with jointly issued announcements soliciting research and joint consideration of funding issues. The Department-wide task force on Alzheimer's disease continues its coordinating role and last Spring sponsored a National conference bringing together families and research investigators to help set the research agenda for all of us.

Mr. Chairman, I thank you for the opportunity for testifying on research efforts in Alzheimer's disease. I shall be pleased to answer any questions that you and the members of the subcommittee may have.

Mr. Ridge. Thank you very much, Doctor. I am glad your testimony highlighted the acceleration of interest and commitment at the Federal level to research and which is as much a product of the work of the witnesses, the kinds of people that have testified today and previously, by creating a growing awareness among legislators and public policymakers.

We thank you and thank you for the optimistic note with which you leave us.

I now would like to introduce to you Attorney Charles C. Bell. Attorney Bell is an attorney in private practice in Pittsburgh, PA, and for a variety of reasons has a professional and personal interest in Alzheimer's disease, and we welcome you, Attorney Bell. We are sorry that the Redskins beat up on the Steelers. We are glad you showed up anyway.

STATEMENT OF CHARLES C. BELL, ATTORNEY AT LAW, WEST MIFFLIN, PA

Mr. Bell. Well, thank you very much, and, first of all, Mr. Lundine and Mr. Ridge, I certainly thank the subcommittee for holding these hearings and for the continuing interest of the Committee on Aging and the subcommittee, in to the national tragic plight of Alzheimer's disease, and also for the personal privilege and opportunity to testify before the committee today concerning the legal aspects and ramifications of Alzheimer's disease, a significant area which is frequently overlooked by families.

And, as for my personal interest, you notice that my last name happens to be the same as the first witness of the second panel, whom Dr. Lebowitz has come between us today.

In my previously submitted written testimony, I described a great number of legal issues which are engendered by the patient's condition, and since I notice I am listed—our panel is listed as "The Response" to, in a sense, the witnesses which have gone before and the response to what the law has been responding to the problem, I just would like to particularly focus on a couple of areas and bring them to the committee's attention.

One problem which is dealt with by the practicing attorney with the Alzheimer's patients is the matter of substitute decisionmaking authority. The individual afflicted with Alzheimer's disease, his ability to make decisions concerning money, concerning personal habits, attainment of medical treatment, becomes less and less, until the point is reached where the patient is no longer able to make these decisions for himself.

Traditionally, the law has had a couple of remedies, one of which has been a guardianship or a conservatorship, which is a State remedy through the State court, whereby an officer of the court is appointed to make these decisions for an individual who is determined to be incompetent.

Another traditional way in which authority has been delegated has been through a trust agreement where the finances of the patient are managed by a trustee for the benefit of the patient.

Now, in Pennsylvania, particularly, we have been very fortunate that a couple of years ago, the State legislature adopted the durable general power of attorney. Traditionally, the power of attorney has been an agreement, a document, whereby authority is delegated to another individual to act on behalf of the person giving the power, the principal, if you would.

Traditionally, the authority to act under a power of attorney ended when the person giving the power, the principal, became incompetent. However, Pennsylvania has adopted the durable power of attorney which, assuming that the necessary language is included in the document, the authority to act on behalf of the principal can last beyond the time of incapacity or incompetency and continue up to the time of death, thereby in most instances preventing the necessity of having to go to the court for an appointment of a guardian.

More interestingly, in Pennsylvania, there has also been the adoption of a medical power of attorney in conjunction with the durable power of attorney. Traditionally, the power of attorney was limited to financial and property decisionmaking. The medical power of attorney can also include the authority to make agreements on behalf of the principal for nursing home care, for hospital care, consent for treatment, for anything in Pennsylvania theoretically, except for psychiatric commitment, which, in and of itself, is governed by State law and even a guardian cannot commit an individual against his will for psychiatric treatment.

So, this is a very fine document. Not only can it avoid court battles or court problems, but it gives the individual at the time he executes the power the opportunity to think about who he would want to make decisions for him, and the extent to which this person may have the decisionmaking authority to act on his behalf. This is a very useful document. I recommend it to many of my clients, particularly those where there is a long-term care problem in the family, such as Alzheimer's disease, and I think it is an efficient and necessary document. Almost as necessary as the will, if you would, in this day and age, and I think this has been one more enlightened thing that our State legislature has done, and in this regard, I think Pennsylvania is truly a leader.

A second aspect of my practice deals with financial planning, which, for the lower middle and middle income family is planning for long-term care engendered by Alzheimer's disease.

The medical assistance program in Pennsylvania and throughout all the States is part Federal regulation/part State regulation. In Pennsylvania, there is a certain entitlement that has to be reached before resort to medical assistance benefits can be had, one of which is the income level.

You are looking at the husband and wife situation where, say, they have a combined savings of $60,000 or $70,000 in cash and property, exclusive of the marital household, presumptively half the value of that property has to be used for an individual who is ultimately seeking medical assistance benefits before the assistance can be given in the joint husband and wife situation.

Now, also, the income, once medical assistance is made, the income of the institutionalized person has to go for his care and for this generation of married couples this becomes a severe burden on the wife because this generation of wives are now in the prime Alzheimer's age when their husbands are stricken. They are of the generation who were not employed outside the home. They really have no retirement income except for maybe a derivative, Social Security retirement amount from their husband's account.

The husband has the big Social Security check, the husband has the big pension. If you split the assets, so the wife is left with half the savings, she may only have $250 to $300 in Social Security income to maintain herself, so she is dipping into the rest of her assets anyway to try to support herself and eventually she becomes pauperized.

The exemption of the family home can be a benefit unless or until they need to sell the house during the spouse's joint lifetime, if he or she is on medical assistance. At that point, the State then steps in and says what is half of the value of the marital home, which then has to be spent on the care of the individual who is receiving medical assistance benefits.

Now, these regulations vary from State to State. Now, at least Pennsylvania recognizes the presumption of 50/50 between husband and wife. Other States do not. If both parties have to spend down until the total level is reached, the joint assets in total have to be spent for the ill spouse, which, in other States, engenders divorces, you know, attorneys advising couples in that situation that you had better get a divorce, you had better get all the assets transferred in the name of the well spouse, to protect yourself from the financial devastation.

One of the things I discuss with families is the fact that if assets are transferred to the well spouse, more than 2 years before the date of medical assistance application, this is a regulation in Pennsylvania, you are dealing with a 2-year transfer rule. If I were to give my wife $1 million today and 2 years and 1 day from now, I need to be in a nursing home, the State does not ask any questions as to what happened to the $1 million, they only ask did you transfer anything within the last 2 years, and the answer truthfully is "no," then I am on assistance.

Now, that may be an inequitable situation, but at the same point, we are dealing with a situation where the only form of third-party reimbursement which is available is medical assistance and you are dealing with a joint economic catastrophe and why, in theory, should the well spouse go down the drain financially along with the ill spouse, particularly from the situation which nobody was at fault for creating?

One of the drawbacks with—let me tell you, I do not like, you know, in a sense, having to do things like that. I mean, it is the law. You are dealing with arbitrary rules. However, I can advise individuals to take advantage of that as I would advise them to take advantage of tax rules or inheritance laws or anything else, that is fine.

But, I am frustrated because this is what has to be resorted to in the absence of any comprehensive long-term care reimbursement policies in this country, on the part of the Federal Government, on the part of the private health insurance.

Medical assistance, by the way, is not the promised land in terms of care. Discrimination does occur to the assistance patients in nursing homes, you know.

Mr. Morrow was just telling me that in Erie, the Medicaid reimbursement rate is $33 a day, in Pittsburgh, it is $44 a day, but the average nursing home is charging $55 to $70 a day. You do not have to be a Ph.D. in economics to figure out who is going to get the care and who is not going to get the care, and your nursing home accessibility to medical assistance patients is limited. In a sense, you sort of lose some of your rights in the nursing home as an assistance patient because if you create a ruckus with the administration if you do not like how your patient is being treated. The administrator can look at you with a straight face and say fine, take them elsewhere, and you do not really have another place to go when you are on assistance.

Younger onset patients have a severe problem with economic security because of the Alzheimer's. Their employers sometimes "wrongfully" discharge them as being an alcoholic or are pushed into an early retirement rather than the disability retirement for which there are economic ramifications.

On disability, you would continue to rack up time under the pension program and so forth, whereas if you are on an early retirement, you are taking a reduced retirement rate or you may be retired for a couple of years before you get your pension benefits.

Same thing with Social Security disability. Eventually, it can win before the administrative law judge, but you can run into claims representatives who are insensitive to Alzheimer's disease and delay the granting of necessary benefits for the benefit of the patient.

Veterans hospitals are running the same regulatory problems of trying to keep patients in veterans hospitals who deserve to be there through its veterans' responsibilities, and I can go on and on. I am really giving a very quick overview, but what I do want to say is, of course, the law does not exist in a vacuum, it is not—the only laws that were handed down from above were the Ten Commandments. Otherwise, the laws are a reflection of society.

I, as an attorney, can only do so much in response to these problems, to try and help the families. Government lawmakers, of which you are 2 of 535, also can have a responsibility as law-givers in having a response under the law to try to help ameliorate some of the problems which families and their loved ones are undergoing through the tragic plight of Alzheimer's disease, and I commend your serious attention to all the testimony, which has been presented, as we go through these hearings, that our record continues to build, that somewhere along the line, there will be an appropriate response that the next generation will not have to go through what this generation is suffering.

Gentlemen, I appreciate the time. Thank you very much.

[The prepared statement of Mr. Bell follows:]

PREPARED STATEMENT OF CHARLES C. BELL, ESQ.

I am Charles C. Bell, an attorney in private practice in Pittsburgh. For personal and professional reasons, I have been deeply involved with various aspects to Alzheimer's disease since 1979. A large portion of my practice is devoted to counselling families of Alzheimer's patients on patient and family rights and responsibilties. My counsel primarily entails lawful delegation of finanical estate and personal care decision-making by the patient and financial planning for the patient and family and financial estate planning for long-term care costs, as well as other legal issues which arise for the patient.

A. DECISION-MAKING AUTHORITY

I. Power of attorney.—A power of attorney is a legal document through which the person giving the power (the principal) executes a document giving authority to another (the attorney-in-fact) to act on his behalf. The Power of Attorney may be limited in authority as to what items of business may be transacted or for how long the authority may last.

Generally, it is advisable for the dementia patient to delegate all authority allowable under the appropriate state law. Under a genral power of attorney, the principal can delegate to this attorney-in-fact full authority to handle banking, financial matters, bill payment, transfer of real estate, transfer of stock certificates, and so forth. In addition, the general power of attorney in Pennsylvania and California includes a provisions whereby the attorney-in-fact is given authority to make personal care and medical decisions for the patient, such a signing applications to nursing homes or making decisions to consent to treatment. The power of attorney should contain a clause whereby the authority lasts beyond the disability of the principal, which makes the power of attorney "durable".

The attorney-in-fact need not be a lawyer; indeed, it is generally advisable that a spouse or a trusted child be appointed attorney-in-fact. The principal must have sufficient intellectual capacity to understand the nature of the document he is signing and the authority he is delegating under the document.

The authority or an attorney-in-fact to act under a durable power of attorney ends with the death of the principal, while the authority to act under a nondurable power of attorney terminates when the principal is incompetent

II. Trust agreement.—A trust is an agreement with another individual or a bank whereby the principal transfers his assets to the ownership of the other party (trustee) subject to the terms of the trust agreement. While the terms of the trust agreement may vary, the general purpose of the trust is for the trustee to manage and invest the principal's money, pay his bills, and make financial decisions for him.

The principal must have the intellectual capacity to understand both the nature of the trust agreement and the authority he is delegating to the trustee.

Depending on the terms of the agreement, the trust may end with the death of the principal, or it may have provisions for continuing the trust for the benefit of other relatives or charities favored by the principal.

A trustee has no authority to make personal care decisions for the principal or beneficiary.

III. Guardian.—An individual who has insufficient intellectual capacity to enter into agreements such as a power of attorney or a trust agreement will have to have the court intervene and appoint a guardian to make decisions for him. A guardian is a bailiff of the court.

For a guardian to be appointed, the court must first determine that the individual is an incompetent. In Pennsylvania, this means that the individual, because of the infirmities of old age, mental illness, inebriety, or mental retardation, is unable to make financial decisions or is likely to become the victim of designing persons, and is unable to make decisions concerning his personal and medical needs. To support the petition, there must be a medical opinion by a physician describing the nature of the individual's condition and that, in his opinion, the individual is incapable of managing his affairs.

If the court determines that the individual is incompetent, guardians are appointed for him. Guardian of the estate is responsible for managing his financial affairs and paying his bills. The court may appoint a family member, an agency, or bank as guardian of the estate. Guardian of the person is responsible for making the personal care decisions for the patient, including determinations as to where the individual should live, what medical treatment should be received, and signing nursing home admissions. Family members are encouraged by the court to serve as guardian of the person.

IV. Conclusion.—Selection of the proper procedure for the delegation of legal authority to act on behalf of a dementia patient requries the advice of an attorney knowledgeable of dementing illness and various ways of dealing with the decision-making crisis suffered by the patient.

This legal planning should also be done as soon as the patient is diagnosed for the earlier the condition is diagnosed, the more likely the patient is able to participate in this planning to express his wishes, and the greater the variety of solutions to deal with this legal problem of delegation of authority. In particular, the durable power of attorney, especially the durable medical power of attorney, provides the most flexible method of delegating decision-making authority.

B. ESTATE PLANNING

I. Introduction.—Another tragic burden affecting the patient and family because of senile dementia is the financial catastrophe which occurs from the general lack of health insurance to cover irreversible, degenerative diseases.

Generally, health and hospital insurance, whether private, quasi-public, or public, share the same limited scope of coverage. The purpose of these plans is to insure acute medical treatment, acute meaning a short-term medical problem requiring intensive medical and hospital care for a short period of time. This philosophy permeates most medical insurance plans, including Blue Cross and Medicare. Also, as a general rule, the "supplemental insurance programs" for the elderly, plans designed to supplement Medicare coverage, are limited to paying for co-insurance amounts which Medicare does not pay for hospital and nursing home care, and for limited additional periods of time spent in these facilities.

II. Medicaid.—Medicaid is a medical assistance program for indigent citizens of the Commonwealth, and is administered by the Department of Welfare. Primarily, Medicaid is intended to provide medical services for welfare recipients, and entitlement to participate in this program is based on income and asset entitlement. There is a special category of Medicaid recipients defined as "medically needy." Under this category, an applicant does not have to have income and assets which fall under the welfare guidelines so long as the applicant's assets are exhausted and his income is insufficient to meet the cost of medical care.

For nursing homes which participate in the Medicaid program, Medicaid will pay for the cost of skilled nursing care and for "intermediate care," conditions resulting from senile dementia which do not require skilled nursing care but does require placement in a nursing home.

To qualify for Medicaid under the category of "medically needy," in Pennsylvania, the applicant must have total assets of less than $1,500. Assets includes anything of a cash value, including the cash surrender value of life insurance policies. In addition, the applicant may set up an irrevocable burial account in the amount of $1,500. An irrevocable burial fund account means that money cannot be withdrawn from the account until death of the Medicaid patient. In addition, the applicant's income must be paid to the nursing home caring for the patient.

The applicant's home is exempt from consideration as an asset so long as a spouse or a legal dependent resides there. Should the spouse or dependent move from the house or die before the Medicaid recipient dies, then the value of the Medicaid recipient's interest in the house must be used for his or her care. In addition, any bank accounts, stocks, bonds, or other cash assets which the Medicaid applicant owns jointly with a spouse, other relative, or any other individual is deemed to be partly owned by the Medicaid applicant, and a partial amount must be used for the care of the patient.

Any transfer of an asset or interest in an asset prior to two years before the date of application to Medicaid, without the applicant receiving full value for the asset, is deemed to be fraudulent, and the amount of that interest conveyed must be used to pay for the patient's care.

Presently, a spouse over the age of 60 is not required to pay support for a spouse receiving Medicaid. A spouse under the age of 60 is required to provide support based on an ability to pay. Also, the separate assets of a spouse over the age of 60 of a Medicaid patient are not presently subject by the Commonwealth to pay for the support of that spouse. Presently, adult children are not required to pay for the support of a parent receiving Medical Assistance.

As a practical matter, Medicaid does not prevent economic hardship from occurring whenever an insurance resource is needed to pay for the care of a senile dementia patient in a nursing home or other extended care facility. First the applicant must have "spent down" his or her assets to the $1,500 threshold. Second, the applicant's income must be paid to the nursing home. This burden falls particularly hard on the wives of senile dementia patients, since their husbands usually have the large retirement income from pensions and Social Security retirement. Wives, therefore, have to dip into their separate assets to supplement their meager Social Security retirement income in order to maintain themselves, and this can lead to severe economic distress.

To protect the unafflicted spouse from total financial ruin, a growing body of thought among attorneys is to advise that the ill spouse transfer his assets, or assets in which he has an interest, to the well spouse, with the hope that the transfer precedes the appropriate regulatory transfer period. Through these transfers, the well spouse is protected from the financial devastation of the staggering costs of nursing home care.

Another practical limitation with Medicaid is that comparatively few nursing homes will accept a Medicaid patient. Many nursing homes find it difficult to meet costs of operation because they feel the rate of reimbursement for skilled and non-skilled nursing home services are insufficient. In some instances, nursing homes which accept a patient under Medicare and/or supplemental insurance coverage will then require the patient to be transferred to another nursing home when these insurance resources have been depleted. Prior to admission, families are encouraged to become familiar with the nursing home policy regarding converting the patient to Medicaid after private resources and insurance have been exhausted. Primarily, the nursing homes which accept Medicaid patients are the state hospitals, public county homes and some parochial homes. There is great concern that the Medicaid patient does not receive quality care in nursing homes because of the insufficient reimbursement rates.

C. EMPLOYEE TERMINATIONS

One tragic ramification of Alzheimer's disease is that the individual can no longer maintain his employment because of his declining cognitive abilities. The employer may conclude that the employee is suffering from a drinking problem or a psychiatric condition, or he may conclude that the individual has a dementia. However, whenever the employer recognizes that the individual is no longer functioning properly in the job, he terminates the employment through dismissal or early retirement. The termination of employment, rather than placing the employee onto company disability, can have a severe economic consequence on both pre-retirement income and pension benefits for the patient and family. Because the patient is not diagnosed at the time of termination, and probably will not be diagnosed for some time thereafter, it is difficult to overturn the prior loss of employment or convert an agreed early retirement to a disability retirement. In addition, the restrictive definition of disability under Social Security prevents many employees from receiving income maintenance from the government as the patient is not defined as being unable to perform any kind of work whatsoever.

D. CONCLUSION

The foregoing discussion touches on the most prominent legal issues affecting Alzheimer's patients. However, there are a number of other problems which would deserve extended discussion. These include: the relationship between a bank and its debilitated Alzheimer's patient; the legal ramifications of the operation of a motor vehicle by an Alzheimer's patient; the severe limitations of damages when the patient is a victim of malpractice by a physician, hospital, or nursing home; patient rights in hospitals, nursing homes, and personal care homes; divorce proceedings brought by the well spouse; questions of mental capacity at the time of business transactions; mental health commitment proceedings; right to medical treatment; right to refuse medical treatment. Indeed, the life of an individual with a diminished or absolute loss of cognitive abilities presents a vast montage of issues which are difficult to adequately resolve.

However, I hope that my testimony raises a number of issues of concern and interest to the subcommittee, and that some of these matters might be considered for appropriate remedial legislation or administrative regulation.

Mr. RIDGE. Thank you very much, Attorney Bell.

I would like to turn over the questioning to Congressman Lundine.

Mr. LUNDINE. Dr. Lebowitz, I was very impressed with the amount of research that is going on and particularly the Department-wide task force idea.

Is there any effort being made to disseminate the information that is being gained by this research, particularly so that average people, as well as physicians, could understand the state of our knowledge about the disease?

Dr. LEBOWITZ. Mr. Lundine, when Mr. Richard Stout collects the names of people who were not able to pick up the material that I brought up with me, they will send the names to me, and I will get more information to them.

Yes, there is a great deal of information that has been prepared for primary care physicians, for specialists in neurology, psychiatry and internal medicine, for other professionals, social workers, psychology, for other people who are important in this system, like clergy, and for the public in general and for the families.

Mr. LUNDINE. I am kind of curious seeing that this is a progressive disease. Is there any predictor that you have indicated that would put a certain category of people into more likely candidates for being an Alzheimer's victim in the future?

Dr. LEBOWITZ. Yes, sir. Age.

Mr. LUNDINE. Other than age?

Dr. LEBOWITZ. No.

Mr. LUNDINE. None.

Dr. LEBOWITZ. None.

Mr. LUNDINE. There has been an estimate that 50 percent of the patients in nursing homes suffer from Alzheimer's disease based on some statistically valid medical diagnostic study.

Is this assessment, in your opinion, objective or is it—is there anything in patient behavior that would allow us to make that kind of a judgment?

Dr. LEBOWITZ. Absolutely. I think we have to begin by recognizing that people in nursing homes are very sick, and that there are many things that are wrong about their physical, mental and emotional condition.

I believe that the estimate of 50 percent is close. It comes from a variety of studies that have been done in a variety of circumstances, and they tend to cluster around that mark.

At the same time, I believe we have got to recognize that there are at least two and maybe three Alzheimer's victims who are being cared for in the community by their families for every one that is in a nursing home.

Mr. LUNDINE. Ms. Bell, your suggestion for a long-term care continuum raises the question that under a Federal reimbursement mechanism, how can we accurately come up with definitions that could be applied so that the criteria for reimbursement is clear?

Ms. BELL. I think when we look to the documentation that is already in existence with the National Institutes of Aging and the

National Institutes of Neurological and Stroke Disorders, for specific data as to what the individual means are, the length of time of the illness, and the studies that are already going on in various States concerning the disease process, and I think we can go to them for some pretty definitive guidelines.

Mr. **LUNDINE**. I am sure you realize the enormous pressure we are under right now as far as Federal spending is concerned across-the-board.

How do you foresee such a reimbursement mechanism could be handled for wide-ranging services without enormous cost and without what I call the boondoggle factor of—which is, you know, the one required television program for all Congressmen is "Sixty Minutes". I mean, we might not know what else is on television, but we had better watch that because we are going to get flooded with all these outraged people that will be yelling at us about some boondoggle or another that Mike Wallace or Morley Safer have ferreted out, and one always has to worry when legislating that no matter how persuasive and how convinced we are that we are doing good, somebody might abuse a program and particularly when there are wide-ranging services, I might say, in which I believe, but which are subject to potential abuse.

Ms. **BELL**. I agree with you, and I certainly am not recommending that we talk about another Medicaid Program. I am talking about a cooperative effort. The families, our private sector, the insurance kind of aid, and the Federal Government in looking at a measure, such as this.

I am not in the Congress, and what I can state just from my own personal experience and from other families' experiences that this is the last resort the families look to, to try to secure remedies, after they have spent moneys on their own.

I mean, our family spent well over $100,000 before we started to accumulate bills that we could not even begin to pay, and if we just take something like the catastrophic insurance program that Pennsylvania is looking at with, what is it, $15 per year reimbursement, I am going to be 40 next year, I cannot buy a policy to protect my husband and my family in the event that I develop Alzheimer's disease, and if we look at something like a $15 per capita assessment of individuals who are over a certain age or who are—I mean, I am not—I am just giving this as an example.

I am saying that I think it could be manageable. I think it could be realistic, and as to the educational aspect that continues to grow about Alzheimer's disease through the National Institutes of Aging and Health, and the American public becomes aware of how much this cost factor is going to be, they will gladly look to something like this as a cost-effective way of providing good care.

Mr. **LUNDINE**. I am interested in following up on that. In the sense that have you had any dialog with the private insurance companies as to their willingness, if there were some kind of Federal safety net under them, in terms of a catastrophic program, would they be willing to get into something like this whose definition and whose even diagnosis is hazier than other things that they insure?

Ms. **BELL**. We have heard from the national level. The one committee that I sit on is the public policy committee, and there have been at least three different insurance companies who are trying market surveys of a limited audience to determine the feasibility of it.

So, I do believe that the insurance companies are looking at this, and the Association of Retired Persons is one of the organizations, I believe, that is spearheading that.

Mr. **Lundine**. Mr. Bell, your testimony is really interesting, and I really want to compliment you not only because of your relationship but as an attorney who is not actively practicing today, one can become very distainful of our profession, and in many respects.

If I could tell a side story. Once, I had a Japanese witness testifying, and I said is there anything else you would like to say. I mean, there is a difference between our country and yours. And, he says, "Yes, order". I knew exactly what he meant.

Mr. **Bell**. Let me hasten to add that during the break, I immediately sought out Mrs. Forhan and told her that attorneys from Pittsburgh do not charge as much as attorneys in Syracuse.

Mr. **Lundine**. So much for your commercial announcement. I really did not want to get into those kinds of commercials, but at any rate, does there exist information available to the public regarding the possible tailoring of legal plans based on certain degenerative medical conditions, such as this one?

Mr. **Bell**. Not really. Most of my knowledge is actually self-made, and from my own research, and a little bit of it or some of it was also through discussion with a few special attorneys who are interested in this area, primarily legal aid lawyers, welfare lawyers, because it is primarily the welfare lawyers who have dealt with medical assistance and Medicare regulations more so than the private bar.

The only publication in Pennsylvania, which even touches on the subject, happens to be a publication which my wife and I cowrote through the auspices of the Pennsylvania Department of Aging.

This is an area of the law which is beginning to grow a little bit, but to my knowledge, any public awareness of this—of these things primarily comes from speaking engagements of myself and a couple of other attorneys in the Greater Pittsburgh area that have knowledge of these things.

There is a need, no question. California, for example, put into effect either by law or regulation, a requirement that Medi-Cal inform husbands and wives of the splitting of jointly owned assets, this is a requirement that they be informed of this. So, there is a need for the dissemination of information among families.

Mr. **Lundine**. Tom, I want to thank you for inviting me and excuse myself. I not only have miles to go before I sleep, but I move slower than the others do, and I have been to a lot of hearings like this. Of course, we do them all the time in Washington, but I think there are a lot of field hearings. Just recently, I have been to field hearings ranging from Fort Worth, TX, to Fanwell, Holland, Boston, MA, and I have seldom seen anything that was as well organized, and I want everybody to know that even though I am the majority member here, it was all organized by Congressman Ridge, and I thank you for inviting me.

Mr. **Ridge**. Thank you. Some of the thoughts and questions raised by my colleague and, again, thank you, Stan, publicly for taking the time under a variety of circumstances, some of which we did not anticipate when I first asked you to join with us, but thanks very much. Appreciate it.

Ms. Bell, you mentioned that, this is quite candid and I do not want to make light of the fact you were honest enough to tell us your age today and what it will be next year, but that when you are 40, as you look around, you will not be able to obtain insurance in anticipation of the possibility of needing this kind of long-term health care. You have got a personal familial history that suggests the need.

Are you denied the opportunity to get insurance because of personal history or the unavailability of such coverage on the marketplace?

Ms. Bell. The unavailability of coverage in the marketplace.

Mr. Ridge. I wanted to—with that in mind, I had a hunch that would be the response.

There are a couple of legislative alternatives that are presently being considered. They do not address specifically the catastrophic insurance, the initiatives that you have proposed, but I would like to share them with you and just get your response.

Some of my colleagues have thought that not only for Alzheimer's disease but in preparation for long-term health care regardless of the disease that we should set up some kind of—we should encourage savings. We should promote something very similar to a health care IRA. Other colleagues have suggested that be it Alzheimer's disease or a disease that requires home health care, spouses taking care of spouses, siblings taking care of parents, whatever, that we encourage that kind of treatment through tax credits so that recognizing that we will not possibly be able to compensate you dollar for dollar, but, indeed, if we could make a modest contribution to that effort to encourage more home health care and more family orientation, at least in the initial stages of any disease, that it would be a worthwhile initiative.

Would you care to comment on either one?

Ms. Bell. Both. I think the idea of the tax credit and the idea of an IRA in health care package, that we can look to now and for the future generations of Alzheimer's victims would certainly be something that would be welcomed among the families and among the at-risk individuals.

Again, every step that you take at the Federal Government in looking at ways, creative ways, of starting to address the financial issues is going to be important because families will not despair, and they will say OK, now, this is one step we have, this is another area that we have to look to, and perhaps the private sector will continue to develop plans.

Mr. Ridge. I want to follow up on that and refer to your written testimony. You indicated, based on experience and possibly personal but others may have related it to you, that Alzheimer's disease victims are often, not always, but often subject to a lower quality of care if their method of payment is Medicaid or similar pubic reimbursement, that is, if you have the personal resources to get the top shelf care, you get it, but if you have to rely on public reimbursement, it may not be the same.

Hopefully, that relates to occasional experiences, but you seem to indicate that it is the—not the exception rather than the rule.

Would you care to elaborate?

Ms. **Bell.** Yes. In many, many families that I have spoken with throughout the country, and my own personal family experience has indicated the fact that once the individual is in a nursing home situation and is in a Medicaid bed, that they are looking at that, as my husband mentioned earlier, they are looking at a dollar cost.

If you are talking about a $45 reimbursement from the Federal Government and you have an Alzheimer's patient who is in a nursing home, requiring a $100 worth of care, and that is not an economy, you have an individual on a gastrostomy or other feeding tube; if you are an individual with decubitus ulcers; an individual whose care is staff-intensive; who has to be turned every 2 hours; who is aggressive; who has to be on medications or restrained. The cost per day for that individual is going to far exceed the $45. While we have had families who will privately pay for a number of years, and the individual continues to decline, both physically and intellectually, the cost of care goes up, the individual's assets are used up, and now the individual is a Medicaid eligible individual, and the cost of care is too high, very often, a nursing home, at that point in time, will look to perhaps removing the individual from the facility or attempting to remove the individual from the facility because they just cannot afford to care for the person.

In my own case, my mother was in a nursing home and then developed a septic shock and severe problems due to a broken elbow and she was in a coma, she was in a coma for 3 years. She had the disease for 12 years, but she was in a coma for the last 3 years.

We kept her at home for the first 9 years, and, so, those last 3 years, she was not a good candidate for a nursing home given the amount of money that they could get from her.

So, she ended up in a hospital environment and the bed that she had mysteriously closed and never opened again, and there was only one bed that was open in a facility, as I have indicated, that would not be acceptable to someone who was on oxygen and needed all of the skilled care. This is not uncommon.

Mr. **Ridge.** Thank you. Doctor, are there major differences exhibited by those afflicted in earlier life as compared to those afflicted later? I know our research has indicated, I am sure yours has, that there are reported cases of people as young as 40 years of age suffering from this disease.

Are there noticeable differences exhibited depending upon age?

Dr. **Lebowitz.** At one point, Alzheimer's disease was used to refer to what was then called the presenile dementias, something that happens earlier than age 65 or so, and after age 65, the later onset form was called senile dementia.

That distinction was dropped a couple of years ago, on the basis of the pathological data, that is that the changes in brain tissue were the same, regardless of the age of onset, but the earlier onset disorder tends to have a more rapidly deteriorating course and more steadily deteriorating course.

Function goes down more regularly and more quickly the earlier the disorder hits. The later it hits, the more gradual, the more erratic and the less predictable is the series of mid-course steps that victims will go through before finally reaching the point that we have heard described so eloquently this morning by the other witnesses.

So, the major differences between the early onset and the late onset form of the disorder seem to be largely behavioral ones, and then those that become associated with the other kinds of changes that we have heard about here.

Mr. **Ridge**. In your testimony, you painted a picture of perhaps not even renewed interest because I know up until a few years ago, the Federal Government and public policymakers generally had not focused in on Alzheimer's disease.

So, I do want to say that you have painted at least a promising picture of the new commitment, the expenditure of some resources, in excess of $50 million.

Would you elaborate for me a little bit about the research facilities, the integration of facilities that you are using? Are you working with private medical colleges? Are you working with support groups that may be available in northwestern Pennsylvania? Do you have willing Alzheimer's patients who are helping you with research?

Could you elaborate for us, please?

Dr. **Lebowitz**. On each of those, I will try to address it.

Alzheimer's disease does not belong to any discipline of science. The brain does not belong to any discipline of science, and we are now in what is generally regarded as the era of the brain in terms of research.

If the last generation of science was the era of physics, the next will be the era of the brain. This great unknown thing that each of us has is becoming something that is fascinating to investigators from every biomedical, behaviorial, and social discipline is currently involved in scientific research.

Generally, the strategy that we follow is to try to get as many of the best minds that we can thinking about this issue, from whatever perspective they are coming, because we do not know what causes the disorder. Therefore, we do not know what route to follow in order to be able to understand how to develop a rational approach to treatment and cure and prevention.

This is being done in medical centers all over the country, on the one hand, and in family service agencies all over the country, on the other. Just this past year, we have had the establishment of 10 Alzheimer's disease research centers, one in Pittsburgh, close to here. We have had the development of a couple of clinical research centers in Alzheimer's disease, looking at mental health behavioral kinds of issues. We have had the development of a set of Veterans Administration geriatric research, education clinical centers, some of which focus on Alzheimer's disease.

The most important thing that people can do is become involved in that research. This research cannot take place without it, and people can generate, patients and their families can generate research in their own communities by going to research investigators who are working in different areas and say why are you not studying Alzheimer's disease.

Not only the Federal Government, but the family groups and the Alzheimer's Disease and Related Disorders Association, is involved in the stimulation of research, that association itself has a research grant program and is supporting investigations around the country. I do not want to leave out the private sector.

The pharmaceutical industry sees this as the next major area for commercial venture, and they pour tens of millions of dollars into what we pour single millions of dollars as they try to develop new drugs. We have heard this morning about the course of the disease lasting 10, 12, 15 years. Imagine the market that is out there, so that there is a very direct commercial interest as well in doing development research.

There is research going on based in support groups that tries to develop ways that support groups can be more supportive, tries to provide to support group techniques to try to predict what the special stresses, the special problems the family care-givers will have, tries to look at the different kinds of situations that husbands have or wives have in caring for the patients or daughters or daughters-in-law and some sons and sons-in-law, but primarily daughters and daughters-in-law, and as they try to balance commitments to their parents to commitments to their own husbands or wives and to their own children.

We are now in four and soon will be five generation family societies, Mr. Chairman, and we do not even have words to talk about what that family is looking like and what those generations in the middle experience in terms of long-term care because the data show very clearly that we do have a large and well-functioning and extremely stressed long-term care system in this country. It is called the family.

Mr. RIDGE. Thank you very much, Doctor.

Attorney Bell, final question. First of all, I want to join my colleague, Lundine, Stan Lundine. One of the criticisms of Congress is that there are too many attorneys, hopefully present company excluded, but I want to commend you for the personal interest, I can understand, but as well the professional followup.

I know there are many demands on your time and your continuing education, and I thought your testimony was remarkable. It underscored a tremendous personal commitment, and I guess I am kind of wondering, as we take a look at some of the generations that Dr. Lebowitz was talking about and the hope that as society—as we improve our society and as people live longer, we can maintain the quality of life.

There is no sense in living longer if the quality of life cannot be maintained. The need for the legal profession to be sensitive to this disease as well as others and to giving, guiding, and planning and arranging legal affairs will become even greater, and I guess I would ask you whether or not the commitment that you have personally is borne by other members of your profession in and around northwestern Pennsylvania or if you see somewhere in the American Bar Association the same kind of impetus? If we are worried about—if we want the physicians and the researchers to be concerned about it and the home health care delivery system and the nursing care, do we have the legal profession as tuned in as it should be?

Mr. BELL. Overall, Mr. Ridge, no, it is not.

You know, there are different varieties and different attorneys, of course. As an attorney, I get frustrated dealing with attorneys from—representing other clients, trying to do stock transfers with the durable power of attorney, for example. You know, there are about 35 percent of stock agents that will refuse to accept the power of attorney, even though it is perfectly valid under State law because they have some sort of legal opinion that says reject this.

In dealing with banks, with a prepared power of attorney document, walk in with a power of attorney, which is well prepared, legal, covers the waterfront, and the bank is—will not accept that document because the patient cannot sign their three by five signature card, and, therefore, will not allow the attorney-in-fact to have their name put on the account unless or until the three by five signature card is signed.

These are small factual problems. Try to deal with the Social Security Administration through a power of attorney. Through a court-appointed guardian, in fact. Cannot be done because the Federal rules pertaining to Federal benefits, some of which does not protect the patient, but it reaches the point of iron bureaucracy, so to speak.

So, in this respect, there is some difficulties. The knowledge throughout the legal profession generally is, as I say, quite limited. This is not something that is taught in law school, you know. For years, the complaint has been that dementia has been overlooked in medical schools and 5 years ago, there were 150 medical schools and only one geriatric chair.

Now, you sort of run into the same problem with this particular aspect of the law, that there is not even a two or three credit course in law school that is devoted to the problems of the mentally disabled or the mentally infirm.

So, there is a training aspect that is involved here. Sometimes, I think the attorneys have understood and try to deal with this problem are self-educated in this area by dealing with the regulations, by looking for the nuances, and that is how the education begins.

There is no question, however, that there is a need to further educate the legal profession. It is sort of interesting at times when I go into court on different matters. You know, judges have asked me to explain Alzheimer's disease to them, even in the presence of the doctors who are testifying, because they know my involvement with Alzheimer's disease in Pittsburgh and have matched it with the ARDRA.

Not only with that, but to try to get a handle on the legal situation. Just very simply, I have a divorce case, nothing to do with Alzheimer's, but a gentleman who is severely brain damaged from a suicide attempt, his wife is divorcing him.

The judge's initial reaction was to give the wife all the money out of the marriage because he is in the V.A. without recognizing the ramifications that the V.A. is kicking people out of the long-term care unit, this gentleman with no exception that there are rights here which have to be protected.

I hesitate to say that an attorney with a different sensitivity might have felt sorry for the wife and gone along with this, but this is the sort of thing that needs to be inculcated in the legal profession.

Mr. **Ridge**. I appreciate that. Again, I want to reiterate the thanks of Congressman Stan Lundine to this group and to all of you who took the time to attend. It is quite obvious from the testimony, be it personal, medical, professional, that we have got a long way to go in dealing with Alzheimer's treatment and care and public policy in response to it, but I think that meetings such as this and, more importantly than meetings such as this, the involvement of the people that you have seen here testifying and the involvement of people such as yourselves who took the time to become more familiar with it and who took the time to participate in the forum, is the real first step toward public policymaking.

And, again, to all the panelists, the second panel, and I see some remain from the first panel, my heartfelt thanks to you for taking the time and making the contribution to this discussion, and with that, we will declare the hearing adjourned.

Thank you.

[Whereupon, at 11:49 a.m., the hearing was adjourned.]

APPENDIX

WILSON'S PERSONAL CARE HOME,
West Middlesex, PA, December 1, 1985.

We, as owners and operators of Pennsylvania licensed personal care homes feel we can play a large part in supplying a third choice for someone who has Alzheimer disease and their families. Of course, the first choice should be to keep someone in their own home as long as there is a family who can take care of them. But what happens to the person who has no family, or has out lived their family, or the family who can no longer take the strain of 24 hour constant care and worry? So often families need a week off now and then to just rest.

The second choice we have been told is a Nursing Home. This is also fine, if the person requires nursing care at the average cost of $65 to $75 per day. If you fill the nursing homes with people that are in the first few stages of the disease, then where are you going to put them when they get real bad and they really need skilled or intermediate care?

We, in Pennsylvania, would like to offer a third choice. These people, if they qualify, could function in a Pennsylvania licensed personal care home for months or even years at the average cost of $15 to $30 per day.

These homes are inspected by labor and industry. Their main concern is the safety of the building. Some of their requirements are smoke and heat detectors, fire escapes from second floors, safe furnaces, safe hot water tanks, closed stairways, fire doors, exit doors opening out, not in, and many more. It is an honor and privilege to up-grade your home to meet these standards and receive their license to hang on your wall.

We are also inspected yearly by Department of Public Welfare. Their rules concern safety of the resident. Some of their requirements are, the medicine must be kept under lock and key, files of the residents must be kept in order, doctor's certification needed for each resident and must be renewed yearly, stating that the resident is able to function in a personal care home and does not need skilled or intermediate care, menus posted, staff requirements must be met, monthly fire drills, planned activities, and these are just a few that we have. These are all good rules and should be followed. Most of us try very hard to keep our homes up to the standards expected of us, so we can also receive our license from Department of Public Welfare. What do we offer for the Alzheimer's resident?

We offer 24 hour supervision, in a family-like atomosphere, nutritious meals, laundry service, hair and nail care, help with medication, planned activities, personal contact with our residents on a 24 hour basis. We have had 5 Alzheimer residents, at one time in our home. They need a lot of love and understanding, constantly need reassured that we love them and want to take care of them. You hold them in your arms and cry with them, you sympathize with them. We have some in the state of confusion, asking that day it is, what time it is, when are they going to eat, maybe 5 minutes after they have just eaten. We have those that realize something is happening to them but what? Days are long for these people. You give support to the families, either when they come or call. The family also need reassured that they shouldn't feel guilty about not being able to take care of a loved one in their own home.

In our home, we find when these residents reach a level when they start referring to me as Mom, they seem to stabilize for a while. They like to be tucked in at night and kissed and told, "I love you." They look up at you and smile and say "I love you too." They know you care. They like to sit and read. When we find the magazines are getting too hard, we get out my grand-children's golden books. They love to sit and read to someone, or have someone read to them. We play games, like old maid. They like to win, perhaps they are hoping and praying like I, that in the end they will win.

It takes a lot of love, patience, and understanding to take care of these people. With work-shops, seminars, and lectures, we can become even better providers.

Please, we have so much to offer these people and their families. Give us a chance to offer the third choice to them. Some of them can function in a personal care home. A home that gives personal care plus tender loving care.

I extend an invitation to each of you to drop in at our home at 326 Main Street, West Middlesex in Mercer County, PA and see first hand how our residents are treated and the care they are given.

Thank you very much for giving me the time to explain why we would like to offer our services.

Yours truly,

GRETCHEN WILSON.

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